A Clinic for People with Epilepsy in rural Tanzania:

Why do Patients default from Follow up and what can increase adherence-behavior?

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Zusammenfassung

In einer Epilepsieklinik in der ländlichen Gegend im Norden von Tansania kehrten nur 44,2 Prozent (149/337) der registrierten Patienten zur Klinik zurück, obwohl die Therapie-Erfolge zufriedenstellend waren.

Diese Dissertation untersucht die Ursachen für die mangelnde Adhärenz und zeigt Möglichkeiten auf, die Adhärenz zu verbessern.

Die Patienten wurden zu einer Untersuchung und einem Interview anhand eines Fragebogens in Ihren Dörfern aufgesucht. Ausgehend von einem voruntersuchten Kollektiv von 337 Patienten, wurden, um eine Stichprobe von der Größe zu formen, die in sechs Monaten voraussichtlich bewältigbar war, 147 Patienten durch ein statistisches Zufallsprinzip ausgeschlossen. Es blieben 190 Patienten. Von diesen waren neun Prozent (18/190) verstorben, 14,2 Prozent (27/190) waren verzogen oder konnten aus anderen Gründen nicht angetroffen werden. Zwölf Prozent (23/190) der Patienten wurden wegen unzureichender Datenlage letztlich weggelassen.

Die verbleibenden 122 Patienten sind Gegenstand der vorliegenden Studie. Als Nicht-Adhärente wurden 45,9 Prozent (56/122) der Patienten dieser Gruppe klassifiziert; 54,1 Prozent (66/122) Patienten, die regelmäßig erscheinen, als Adhärente.

Der Vergleich zeigte, dass die Wohnorte der Nicht-Adhärenten im Durchschnitt 11 km weiter entfernt von der Klinik lagen. Nicht-Adhärente waren im Schnitt über zwei Jahre jünger als Adhärente und öfter pubertierend. Der größte Teil der Nicht-Adhärenten (45/56; 80,4 Prozent) nahm keine Medikamente gegen Epilepsie ein. Diejenigen, die Medikamente einnahmen, erhielten die Tabletten von Dispensatorien. Die Adhärenten waren zum allergrößten Teil unter regelmäßiger Medikation (60/66; 90,9 Prozent).

Es gab Anzeichen, dass Nicht-Adhärente eher eine traditionelle Lebensweise pflegten und ökonomisch schlechter gestellt waren. Außerdem berichteten sie etwas öfter als Adhärente über eine unregelmäßige Versorgung mit Nahrungsmitteln.

Die Hauptgründe für ein Fernbleiben von der Klinik, waren für 37,5 Prozent (21/56) der Patienten, dass keine Anfälle mehr auftraten und sie sich für geheilt hielten, 17,9 Prozent (10/56) waren nicht mit der Behandlung zufrieden und 12,5 Prozent (7/56) hatten Schwierigkeiten den Weg zur Klinik zu bewältigen. An Dispensatorien angebunden zu sein und dort Medikation zu erhalten, war für 14,3 Prozent (8/56) der Patienten Grund die Folgeuntersuchungen in der Klinik für Epilepsie nicht mehr wahrzunehmen.

Betrachtet man früher erhobene Daten derselben Stichprobe (n=337), ist es offensichtlich, dass diejenigen, die später fernblieben bereits kurz nach der ersten Aufnahme in der

Klinik Termine nicht wahrnahmen, außerdem waren sie bei Registrierung in der Epilepsieklinik seltener unter zuvor begonnener medikamentöser Behandlung.
Um die Adhärenz zu verbessern, empfehlen wir eine weitere Dezentralisierung des medizinischen Systems und speziell der Behandlung von epileptischen Anfällen/Epilepsien bis auf Dorfebene, zusätzlich eine Integration von Epilepsietherapie in die Primary Health Care (unterste Stufe der medizinischen Versorgung in Afrika, die wohnortnah gelegen ist). Für Menschen mit Epilepsie sollten auf ihre Situation angemessene und verständliche Schulungen sowie eine adäquate psychosoziale Unterstützung bereitgestellt werden.

Summary

In a clinic for people with epilepsy in a rural area in northern Tanzania only 44.2 per cent (188/337) of the already registered patients returned for follow-ups regularly, though the response to anti-epileptic therapy had been satisfactory.

This thesis explores the causes of non-adherence in a clinic for people with epilepsy in Tanzania and suggests ways to increase adherence-behaviour. The Patients were searched for in the villages for re-examination and interview by means of a questionnaire.

Based on a collective of 337 patients who had participated in a former study, by statistical sampling, 147 of the patients were excluded, in order to form a sample which could be examined within a period of six months. Of the remaining 190 patients, 9.4 per cent (18/190) had died, 14.2 per cent (27/190) had moved away or could not be met for other reason and 12.1 per cent (23/190) patient were omitted due to insufficient data.

This study examines the remaining 122 patients. Of those 45.9 per cent (56/122) were identified as “Non-Attenders”, 54.1 per cent (66/122) came regularly, named “Attenders”.

Comparison showed, that Non-Attenders lived on average 11 km farther from the Hospital. Non-Attenders were more than two years younger than Attenders and more often pubescent.

Most of all Non-Attenders (45/56; 80.4 per cent) were not on treatment. Those who were, got drugs from dispensaries. Attenders mostly took antiepileptic drugs regularly (60/66; 90.9 per cent).

There were indicators that Non-Attenders lived more traditionally and might be economically weaker, e.g. compared to the Attenders, they more often practiced open defecation or reported an irregular food supply.

The main reasons given for default were: for 37.5 per cent (21/56) of the patients, that seizures had stopped. For 17.9 per cent (10/56), that they were not satisfied with the treatment, and for 12.5 per cent (7/56) that they had difficulties in travelling to the hospital. Treatment in dispensaries was reason for 14.3 per cent (8/56) of the patients not to return.

Considering previously collected data from the same sample, it is obvious that those who became defaulters already had missed appointments soon after registration and they were less likely to be on antiepileptic treatment at time of registration.

To improve the adherence behaviour, we recommend further decentralisation of care to a community level and, additionally, integration of antiepileptic treatment into primary health care. Appropriate education and adequate psychosocial support should be provided for people with epilepsy.

Content

List of abbreviations

AED	Anti-Epileptic Drug
AIDS	Acquired Immune Deficiency Syndrome
Asymp. Sig.	Asymptotic Significance
avg.	Average
CBZ	Carbamazepine
CWE	Child / Children With Epilepsy
EEG	Electroencephalogram
e.g.	for example (Latin: exemplum gratii)
etc.	et cetera
HIV	Human Immunodeficiency Virus
HLH	Haydom Lutheran Hospital
i.e.	that is (latin: id est)
ILAE	International League Against Epilepsy
N	Number
PB	Phenobarbital
PWE	Patient With Epilepsy
resp.	respectively
SD	Standard Deviation
SSA	Sub Saharan Africa
VPA	Valproic Acid
WHO	World Health Organization
yrs.	years

I. INTRODUCTION

1 EPILEPSY

Epilepsy is a common neurological disease which is characterized by a tendency to recurrent seizures. It affects almost 50 million people worldwide and is increasing at a rate of two million new cases annually (WHO, 2003). Approximately 80 per cent of the people affected by the illness live in developing countries (WHO, 2009). While the annual incidence in developed countries is approximately 50 per 100,000 of the general population, in developing countries the number is nearly doubled with 100 per 100,000 (ILAE, 1993).

1.1 Definition of epilepsy and general facts

The definition of epilepsy in literature was rather consistent for some decades: *"A condition characterised by recurrent (two or more) epileptic seizures, unprovoked by any immediate identified cause and thus not due to an acute intracranial or extra cranial condition, is termed epilepsy"* (ILAE, 1993). However, in 2005 the International League Against Epilepsy (ILAE) proposed an enhanced version, phrased by R. Fisher: *"Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure."* The emphasis now lies on an enduring alteration in the brain and the consequences of the diagnosis. Furthermore, modified was that now only one seizure is required for diagnosis, considering a predisposition such as a brain lesion. (Fisher et al., 2005).

An epileptic seizure is defined as a paroxysmal event due to abnormal excessive, hypersynchronous discharges from an aggregate of neurons within the brain. Depending on where the discharges occur und which parts of the central nervous system is affected, the resulting visible expression can vary from not discernible by an observer to dramatic convulsive activity (Lowenstein, 2001).

1.2 Aetiology of the epilepsy

The classification of aetiologies of the epilepsies can be divided into four main categories.

The most common form is called *idiopathic epilepsy* and has no identifiable cause; thus, no gross neuroanatomical or neuropathological abnormality and a genetic origin has not yet been elucidated, but is to be supposed (Shorvon, 2011).
Contrary to that a *symptomatic epilepsy* has an acquired or genetic cause. It is associated with gross anatomic and/or pathologic and/or clinical abnormalities. Also included in this category are genetic or acquired pathologic changes. Infectious diseases (for example neurocysticercosis, meningitis, and malaria) and trauma are common causes for the onset of an epilepsy in developing countries (Pradhan et Yadav, 2004). According to this, symptomatic epilepsies dominate in these regions.
If there are no gross causative neuroanatomical or neuropathological changes, but the predominant cause for epilepsy are specific stimuli (systemic or environmental), this condition is a *provoked epilepsy*. The epilepsies with a marked seizure precipitant and the reflex epilepsies are included in this category (Shorvon, 2011).
Still about 40 per cent of adult-onset epilepsies belong to the last but important category of *cryptogenic epilepsies*, in which a cause has not yet been identified (Shorvon, 2011).

1.3 Treatment of epilepsy

Today, for the treatment of epileptic seizures the following remedies are available: antiepileptic medication, neurosurgery, vagus nerve stimulation and special lifestyle-modifications (Fröscher, Vasella et Hufnagel, 2004). Additionally, after R. Fisher a recent promising therapy for epilepsy is the electrical deep brain stimulation via an implanted neurostimulator system (Fisher et al., 2010).
However, for treating epilepsy by far most common is an antiepileptic medication. After a World Health Organization (WHO) fact sheet, studies indicate that up to 70 per cent of newly diagnosed patients with epilepsy (PWE) can be successfully treated with anti-epileptic drugs (WHO, 2009).
In most cases anti-epileptic drug (AED) therapy does not offer a permanent cure, the purpose of the therapy is to control the symptoms – preferably eliminating the seizures or at least reducing them. Ideally, drug side effects and drug interactions are minimized, thereby supporting and improving the patient's quality of life and ensuring the adherence to the therapy.
The most commonly used conventional AEDs are: Carbamazepine (CBZ), Gabapentin, Lamotrigine, Levetiracetam, Oxcarbazepine, Phenobarbital (PB), Phenytoin, Pregabalin, Topiramate, Valproic acid (VPA) and Zonisamide acid. AEDs rarely used, as add-on, in combination or for special indications are (amongst others, in alphabetical order):

Acetazolamide, Ethosuximide, Felbamate, Lacosamide, Mesuximide, Sultiame, Tiagabine and Vigabatrin. Drugs of choice for an acute therapy within a seizure (or status epilepticus) are Benzodiazepines (Diener, 2012).

After the current the ILAE treatment guidelines, in adults with partial-onset seizures first-line recommended are Carbamazepine or Phenytoin and as second line Valproic acid. In children with partial-onset seizures should be used preferably Oxcarbazepine and in elderly adults with partial-onset seizures Gabapentin and Lamotrigine (Glauser et al., 2006).

ILAE proposes as a definition for drug resistant epilepsy: “a failure of adequate trials of two tolerated and appropriately chosen and used AED schedules (whether as monotherapies or in combination) to achieve sustained seizure freedom” (Kwan et al. 2010). About 25 per cent of patients with epilepsy have intractable seizure disorders. Of those, between 12 and 25 per cent are candidates for surgery (WHO, 2003).

1.4 Epilepsy in history

The oldest discovered detailed description of epilepsy is on a Babylonian clay tablet from the second millennium BC. Babylonians were remarkably exact when describing different types of seizures, which are also recognised today, as well as complications and provocative and prognostic factors and interictal events (Alarcón et Valentin, 2012). However, Babylonians obviously had no knowledge of the functioning of the brain. Seizures were thought to be an invasion of the body by an evil spirit or demon. In the following Centuries and in Roman time the gods were included as possibly responsible for obsessing people.

Hippocrates for the first time in his famous fifth century BC essay, “Morbus Sacer”, took natural causes into consideration and he hypothesised a disorder of brain.

This idea had little influence on the prevailing supernatural view of epilepsy up until the seventeenth and eighteenth century (Alarcón et Valentin, 2012). During the medieval period treatments consisted of prescribed diets, changed living conditions, occasional surgery such as bloodletting, skull trephination (to get the evil spirit out of the head), and medicinal herbs (Gross, 1992).

In the age of enlightenment, the concept of a brain disorder began to take root in Europe. Helped by advances in anatomy and pathology and the development of chemistry, pharmacy and physiology of the nineteenth century (for examples the idea of functional localization within the brain by Ferrier and the discovery of the motor cortex) the scientific knowledge concerning epilepsy grew (Gross, 1992).

In particular, John Hughlings Jackson with his seminal contributions to the diagnosis and understanding of epilepsy in all its forms and complexities paved the way to a modern view of the disease (Balcells Riba, 1999).

However, the firm belief still remained that the origin of epilepsy was vascular. This concept was first challenged by Robert Bentley Todd in 1849 (Alarcón et Valentin, 2012). The idea that focal irritation could cause seizures came from clinical and experimental work, and was furthermore supported by the successful control of seizures by the (sedative) bromides and barbiturates in the late 19th century (Gross, 1992).

Shortly following the invention of the Electroencephalography (EEG) by Berger in 1929, the congruence between abnormalities in the EEG and epileptic seizures was found, as well as interictal changes of the EEG-pattern.

The identification of the role of ionic channels for membrane potential by the Nobel Prize winners (1953) Alan Lloyd Hodgkin and John Humphrey contributed to the understanding of neuro-pathophysiological processes (Alarcón et Valentin, 2012).

The introduction of phenytoin in 1938 showed that non-sedative drugs could be effective in controlling seizures as well, and the development of in vivo seizure models widened the scope of agents tested for their efficacy against epilepsy (Gross, 1992).

Historically speaking, the perception of epilepsy as a dysfunction of brain - in principle treatable, and set apart from supernatural interaction, is also quite new in Europe (Ozer, 1991). The belief in demonic possession can be traced through medieval and early modern periods (Kemp et Williams, 1987). And even after recognizing a physical and anatomical context, a wariness of persons with epilepsy was universally existent. Only within the last two or three decades is a person with epilepsy portrayed in literature and in films as a “normal” and likeable human being (Ozer, 1991).
It seems as if we were only a short hop from the African (in this case Tanzanian) conception of epilepsy, which is subsequently described in detail.

1.5 Epilepsy in developing countries with special emphasis on Tanzania

The prevalence of epilepsy in developing countries has been thoroughly explored in several studies in the last decade. Compared to the mean prevalence of approximately 8.2 per 1,000 of the general population worldwide, the prevalence in developing countries is significantly higher with more than 10 per 1,000 (WHO, 2001).

Rural regions are usually even more affected by the impacts of the disease than urban areas. This can be explained considering that in addition to the general problems of developing countries (pre-/postnatal pathology, frequency of premature birth, infection with the human immunodeficiency virus (HIV), meningitic infections, parasite affection (Jallon, 1997)), there are predisposing factors for an adverse progression of epilepsy such as bad hygienic conditions, reduced availability of medication, a widespread belief in traditional medicine and a lack of general and medical education (Jilek-Aall et Jilek, 1993). As a crude measure one can assume the prevalence in developing countries to be about twice the prevalence in developed countries. Certain regions of Tanzania show the highest prevalences known worldwide. Prevalence rates may but vary widely between countries and even between regions. An analysis of door-to-door surveys in Sub-Saharan-Africa done in 2005 by Preux et Druet-Cabanac, revealed a median prevalence of 15/1,000 with a range from 5.2 to 74.4/1,000 (Preux et Druet-Cabanac, 2005). In Tanzania, Jilek-Aall (1965) found a very high prevalence of epilepsy in the Mahenge area already 40 years ago (Jilek-Aall, 1965). This finding started to point out the problem of epilepsy in developing countries to the developed world. She estimated the prevalence to be about 20/1,000 inhabitants at that time which was confirmed almost 30 years later by a community-based survey (Jilek-Aall, 1965; Rwiza et al., 1992). The latest study, situated in the catchment area of the Haydom Lutheran Hospital was done by our research group, where the prevalence was found to be 10/1,000.

About 50 million people suffer from epilepsy worldwide, 80 per cent of them are living in developing countries and up to 90 per cent of latter remain untreated (WHO, 2001; Meinardi et al., 2001). The non-treatment is due to poor infrastructure, insecure medical supplies and lack of specially trained medical staff among others.

But also the completely different concept of epilepsy in the rural African population and the resulting lack of acceptance of the disease contribute and complicate an adherence with treatment. The majority opinion is that epilepsy is a punishment for sins, a curse or bewitchment, a contagious disease or an evil spirit who haunts the person. These traditional concepts often lead to rejection, discrimination or even ostracism throughout many communities in developing countries (Jilek, 1979; Jilek-Aall et al., 1997; Jilek-Aall,

1999; Rwiza et al., 1993). As a consequence, many patients are hidden by their relatives, considered as a shame for the family (Jilek-Aall et Jilek, 1993).

Rural African people, who suffer from epilepsy, commonly seek traditional healers, who are considered the true source for cure. 80 per cent are treated exclusively with methods like scarification or herbal treatments, mainly by inducing vomiting to get rid of the “spirit who upsets the stomach” (Carod et Vazquez-Cabrera, 1998). A wide-spread point of view among the African people is that hospitals exist for treating physical injuries only. There is still big mistrust in hospitals for treating epilepsy or other “internal” diseases.

2 ADHERENCE TO MEDICAL TREATMENT

2.1 Definition of adherence to medical treatment

According to Oxford dictionary, to adhere means in British as well as in American English: to stick fast to (a surface or substance), to believe in someone/something, to follow the practices of someone, to closely follow, observe, or represent someone (Stevenson, 2010)

It origins in the Latin word *"adherere"* that can be translated as to adhere, to stick, to cling/cleave to; to hang on; to be attached/concerned/involved.

The term "adherence" was introduced by B. Blackwell (Blackwell, 1976) and replaced the term "compliance" in medical terminology. Recently the term is preferred in academic literature as it makes clearer the active part of the patient (Osterberg et Blaschke, 2005). This replacement was generally accepted the last few years.

Adherence comprises not only medication, but also multiple health behaviours that extend beyond taking prescribed pharmaceuticals. Including, that adherence had to reflect special behaviours (like for examples: seeking medical attention, fulfilling prescriptions, taking medication appropriately, attending follow-ups) as well as the relevance of an effective treatment-relationship, finally the WHO agreed on the following definition:

"The extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (WHO, 2003).

In most adherence-research adherence is limited to the taking of prescribed medication, presumably because this is easiest to measure. Therefore, in the majority of quoted literature, authors refer to the regular intake of medication. However, this study does not only deal with taking drugs but deals with adherent behaviour in general: conducting follow-ups, following suggestions, et cetera. Nevertheless, nearly all the patients of this study who didn't return for follow-ups also no longer took AED.

2.2 Measurement of adherence to medical treatment

Although an accurate assessment of adherent behaviour is necessary for a successful treatment and assessing changes in condition and adjusting medication no standard for measuring adherence behaviour exists (Farmer, 1999).

Approaches were made to ask providers and patients for subjective ratings. This failed because providers generally overestimated patients' adherence and in the fact that

patients reported their own behaviour inaccurately. Another subjective means was to apply a standardised questionnaire. Still, the characteristics of single patients were unreliable predictors of adherence behaviour. Objective methods appear to be an improvement. They are not widely applicable because they are either expensive (for example electronic monitoring devices, which record the time when a medication container was opened) or not valid (for example biological markers added to medications and their presence in blood or urine) as influenced by factors like diet, absorption and rate of excretion (Farmer, 1999).

In a review of the WHO it is summed up: *"Finally, no single measurement strategy has been deemed optimal. A multi-method approach that combines feasible self-reporting and reasonable objective measures is the current state-of-the-art in measurement of adherence behaviour."* (WHO, 2003).

2.3 Dimensions affecting adherence to medical treatment

To describe how adherence as a complex behavioural process is determined by multiple factors, a model of five dimensions was adapted.

This model can elucidate, that the view of patients as responsible for themselves is misleading. Patient-related factors are just one determinant (Figure 1) and various other factors also influence a patient's possibility to adhere (Haynes et al., 2002).

Figure 1: Factors affecting adherence according to a review of the WHO (2003)

2.3.1 Social and economic factors

Though worldwide the socioeconomic status has not consistently been found to be an independent predictor of adherence, especially in developing countries poor people must choose between competing priorities, even when they are sick.

The review of the WHO identified these factors as having a significant effect on adherence: poor socioeconomic status, poverty, illiteracy, low level of education, unemployment, lack of effective social support networks, unstable living conditions (also living in a country at war or after war), long distance from treatment centre, high cost of transport, high cost of medication, changing environmental situations, cultural and lay beliefs about illness and treatment, and family dysfunction (WHO, 2003).

2.3.2 Health care team and system-related factors

Many factors have been identified that effect adherence to treatment. Those being particularly negative as predictors were specified: poorly developed health services with inadequate or non-existent reimbursement by health insurance plans, poor medication distribution systems, lack of knowledge and training for health care providers, overworked health care providers, lack of incentives and feedback on performance, short consultations, weak capacity of the system to educate patients and provide follow-up, inability to establish community support and self-management capacity, lack of knowledge regarding adherence and effective interventions for improving it (WHO, 2003; Leventhal et al., 1997)

2.3.3 Condition-related factors

Condition-related factors are illness-related challenges a patient has to overcome. Strong determinants are the severity of symptoms, the level of disability (physical, psychological, social and vocational), the rate of progression and the severity of the disease. Co-morbidities, such as depression and drug and alcohol abuse, can impair good adherence behaviour (WHO, 2003).

2.3.4 Therapy-related factors

The therapy itself (often medication) also has an impact on the capacity of a patient to adhere. These were found as negative predictors: a complex medical regimen, long duration of treatment, previous treatment failures, frequent changes in treatment, the immediacy of beneficial effects, side-effects, and the non-availability of medical support to deal with side effects (WHO, 2003; Claxton et al., 2001).

2.3.5 Patient-related factors

Patient-related factors represent the resources, knowledge, attitudes, beliefs, perceptions anxieties and expectations of the patient.

Age inconsistently affects adherence. Adolescents are less adherent than younger children, which may reflect rebellion in this age group. The adherence of infants and toddlers is largely determined by the ability of the parent or guardian to understand and follow (Burke et Ockene, 2001).

The adherence of elderly people is determined by illness-related factors (also forgetfulness) and social factors. In this age group the adherence behaviour can hardly be averaged (WHO, 2003).

2.4 Examples of adherences to medical treatment in long-term therapies

While good adherence-rates are observed in some short time-therapies for example in antibiotic treatment of respiratory tract infections (Kardas, 2002), adherence in long-term-therapies (or even life-long therapies) are generally worse. These treatments are a challenge for both the patient and the representative of the health care systems. Numerous research studies show that a strong effort is undertaken to solve this problem.
After the review of the WHO in developed countries, adherence to long-term therapies in the general population is around 50 per cent. It is much lower in developing countries where then already limited treatment resources were underutilised or wasted. Unintentional errors in taking medication are made by 50 to 90 per cent of patients (WHO, 2003).
Outlined below are four examples of adherence in chronic diseases after a review of the WHO concerning adherence in long term-therapies. It refers not only to developing countries but was reviewed worldwide.
Chosen are HIV as an infectious disease, depression as a mood disorder and diabetes as a common diseases prevalent especially in developed countries.

2.4.1 Human immunodeficiency virus - infection

For patients affected with HIV a potent medication known as “highly active antiretroviral therapy” (HAART) is available. It has clearly proven effective in reducing viral load and improving clinical outcomes. It is a very complicated multidrug regime prescribed for conditions requiring continuous open-ended treatment (Haddad et al., 2000).
Adherence in this infectious incurable disease is the decisive factor in treatment success, thus to achieve a durable suppression of the virus. Very high levels of adherence (e.g.≥ 95 per cent) are required. Mills and colleagues found that none of the individuals with adherence greater than 90 per cent progressed to Acquired Immune Deficiency Syndrome (AIDS), contrary to 38 per cent and eight per cent of those with adherence rates ≥ 50 per cent and 51–89 per cent, respectively. However, a large number of medications is involved, the dosing requirements are complicated, and the tolerability is often poor (Mills et al., 2006).
Recent studies of patients with HIV/AIDS have reported adherence rates similar to those seen for other chronic diseases. On average approximately only one-third of the affected patients worldwide are said to take their medication as prescribed (Mills et al., 2006).
As causes for non-adherence E. Mills and colleagues found the following in a review study: fear of disclosure, forgetfulness, a lack of understanding of treatment benefits,

complicated regimens, and being away from their medications. These were consistent barriers to adherence across developed and developing nations (Mills et al., 2006).

2.4.2 Depression

Depressive disorder is one of the most prevalent forms of mental illnesses characterised by persistent low mood and other symptoms including sleep disturbance, loss of appetite, suicidal thoughts, impaired concentration and attention, guilt and pessimism.

For the treatment of this disorder, both psychological intervention and antidepressant medication have proven efficacy. Today, the most common form of treatment worldwide is the antidepressant medication

According to guidelines antidepressant medication should be taken for at least six months after remission of symptoms of a first episode. When two or more episodes occurred, long-term preventive treatment is suggested.

After the WHO-review up to two-thirds of depressed patients who started a therapy with tricyclic drugs stopped taking them within a month (WHO, 2003). In another study is reported that only 20 per cent of patients who had been prescribed tricyclic drugs filled four or more prescriptions within six months; 34 per cent of patients who had been prescribed newer antidepressants did so (Cramer et Rosenheck, 1998).

2.4.3 Diabetes

Diabetes mellitus is an endocrinological disease, which causes a decreasing excretion of insulin. Diabetes type 1 results from an autoimmune reaction and mostly occurs in young people (under 20 years). Diabetes type 2 often affects elderly people and results from predisposition and sugar-overeating. Often type 2 is combined with other diseases of the metabolic syndrome. There are other specific types of diabetes, which are rare (Vermeire et al., 2005).

The treatment of diabetes depends on the type and the stage. Type 1 has to be treated with insulin immediately, in type 2 often lifestyle modification and diet can improve the situation. If this is insufficient, there are various drugs available. In the most severe stadium an insulin-therapy has to be applied. Adherence in diabetes not only means drug and insulin-therapy but also other aspects of self-management such as self-monitoring of blood glucose, dietary restrictions, regular foot care and ophthalmic examinations (Vermeire et al., 2005).

Poor adherence to recognized standards of care is the principal cause of complication development of diabetes. In Europe, only 28 per cent of patients treated for diabetes

achieved good glycaemic control. In resource poor countries the number is presumed to be even lower (WHO, 2003).

2.5 Adherence in epilepsy

Epilepsy is characterized by a tendency to recurrent seizures that affects about 50 million people worldwide. There are effective pharmaceuticals available and studies, carried out in developing as well as developed countries, showed that seizures can be completely controlled for several years in up to 70 per cent of the patients.

When treatment is not successful, it is necessary to establish, if there was an appropriate drug selection as well as dosage or if a refractory disease is the source. Particular attention should be given if non-adherence was the problem. In epilepsy, poor adherence is considered to be the main cause for unsuccessful treatment (WHO, 2003).

Patients who do not follow instructions and do not take medication as prescribed have more often and more severe seizures. Thus, they have a lesser quality of life, decreased productivity, more often seizure-related job loss and seizure-related motor vehicle accidents (Hovinga et al., 2008).

The above can result in an increase of health care costs, a reduced quality of life and poor self-management of epilepsy (WHO, 2003).

According to a review of the WHO (2003), adherence to AED in PWE generally ranges from 20 to 80 per cent. Some studies reported different ranges of adherence for adult patients (40–60 per cent) and for children (25–75 per cent) (WHO, 2003).

2.5.1 Factors affecting adherence in epilepsy

Factors impairing adherence can be grouped into the five dimensions described in subchapter 2.3 (page 9). Mbuba and colleagues conducted a research in a rural area in Kenya, measuring the prevalence of and investigating risk factors for the epilepsy treatment gap. He found out a treatment gap of 62.4 per cent concerning the treatment of epilepsies (Mbuba et al., 2012).

The following table is adapted from a review of the WHO (2003). Listed are only factors with a negative effect on adherence.

Table 1: Factors affecting adherence in medical treatment in epilepsy (WHO, 2003)

socioeconomic-related factors
• long distance from treatment setting
• age: Under 60 years old, teenager
• poverty
• Illiteracy
• costs of treatment
• belief about origin of illness
healthcare team/health system-related factors
• inadequate / non-existent reimbursement by health insurance
• irregular or poor drug supply
• lack of free medicine supply
• poorly developed health service
• lack of information about AEDs
condition-related factors
• forgetfulness
• memory deficits
treatment-relates factors
• complex treatment regimes
• misunderstanding instructions
• adverse effects of treatment
patient-related factors
• disbelief in diagnosis, denial of diagnosis, doubting the diagnosis, delusional thinking
• refusal to take medication
• inconvenience of treatment
• lifestyle and health beliefs
• parental worry about child´s health
• fear of addiction
• uncertainty about the necessity to take drugs
• anxiety about the complexity of drug regime
• feeling stigmatized by epilepsy

Some difficulties such as misunderstanding instructions about how to take the drugs, complex medication regimens, forgetfulness and fear of dependence seem to be quite easy to overcome. Other hindrances, like feeling stigmatized by the epilepsy, inadequate or non-existent reimbursement by health insurance plans and poverty, among others, are a great challenge.

Frequency and duration of seizures and previous treatment failure was found as not influencing adherence behaviour. Also, the severity of seizures was not significantly associated with any adherence outcome, contrary to expectation.

On a worldwide average, families reporting less parental education, illiteracy, lower income and high levels of stressful life events were even more likely to adhere to AEDs. Also elderly people (> 60 years of age) showed a higher rate to adhere.
In addition, some positive factors are satisfaction with treatment, the feeling that it is important to take medication, not feeling stigmatized, simple dose regimes and monotherapy (WHO, 2003).

2.6 Problem of adherence to medical treatment in Haydom Lutheran Epilepsy Clinic

As described in chapter Methods (II.1.2; page 22 f) the founder of the Haydom Lutheran Epilepsy Clinic, Dr Andrea Winkler, had noticed that a decreasing number of epilepsy patients did show up at follow-up appointments. More precisely 55.8 per cent of the patients Dr Winkler had once registered, had not returned for more than one year.
Beside the general adherence problem in chronic diseases, it is a well-known fact that in developing countries ensuring follow-up treatment due to financial and socio-cultural reasons amongst others (Jallon, 1997) proves to be very difficult. On the other hand, it is obvious that to optimize therapy and symptom control, PWE require a regular follow-up and adjustment of their medication.
The initial conditions for PWE at the Haydom Lutheran Epilepsy Clinic seemed to be favorable. Patients did not have to pay for medication. After diagnosing epilepsy, the patients and their relatives underwent a detailed education concerning the aetiology, prognosis and therapy of the disease as well as special precautions. Follow-ups were scheduled.
All the more, we wanted to find out what particular reasons detained patients from returning and how, or if, the clinic could help them to develop a more adequate adherence behaviour.

The purpose of this study was to research the reasons for PWE at the Haydom Lutheran Epilepsy Clinic defaulting on follow-up treatment and discontinuing AEDs. We therefore formulated the following study objectives.

3 STUDY OBJECTIVES

In PWE who used to attend the Haydom Lutheran Epilepsy Clinic our aims were to:

- Identify the reasons of non-attendance to the Haydom Lutheran Epilepsy Clinic by comparing Non-Attenders and Attenders, concerning demographic characteristics, education, economic factors, attitudes and perception of the disease, clinical and social aspects, use of healthcare, treatment.
- Determine possible predictive variables of non-attendance.
- Suggest, based on the results of our study, ways to possibly increase the adherence to medical treatment.

II. METHODS

1 STUDY AREA

The study was conducted in a rural and relatively remote part of Northern Tanzania, within the area serviced by the Haydom Lutheran Hospital (HLH). In Figure 2 the position of Tanzania in Africa is painted red. At the smaller excerpt the study area is localised inside of the ring.

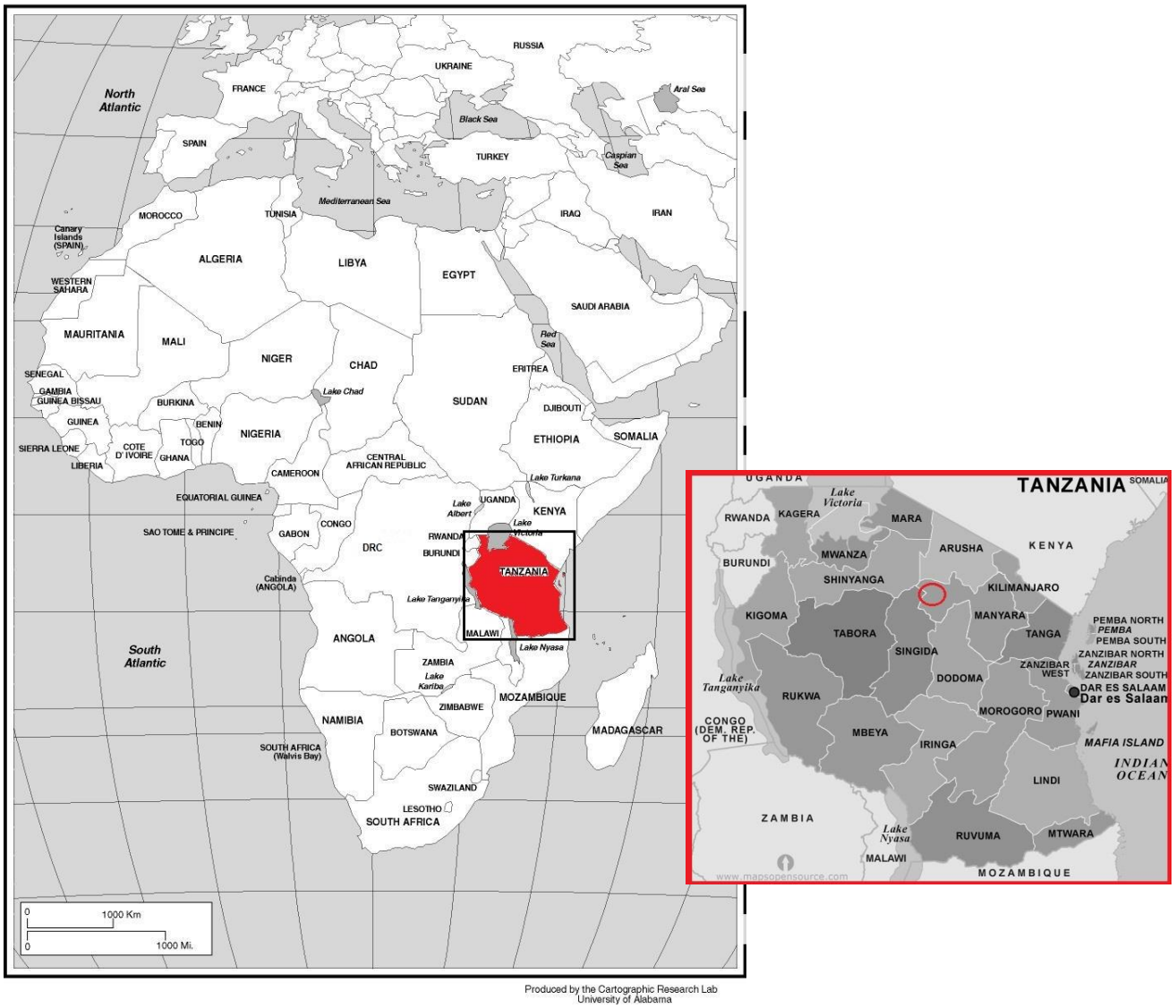

Figure 2: Map of Africa, Tanzania marked. Map of Tanzania, study area roughly marked. (Source: Maps Opensource CC BY 3.0)

People within the region tend to live a relatively traditional lifestyle, with the primary economic activities being subsistence farming and pastoralism. The area is also unique in so far as having the four main language groups of the Africa's mainland present. Of these the three largest groups are: Iraqw (Cushitic), Datoga (Nilotic), and Iramba (Bantu). The smaller indigenous group of Hadzabe (Khoisan) is also represented. Despite this, the main spoken language is Kiswahili, however, many of those who've not had any schooling tend to only speak the local languages (Website of Haydom Lutheran Hospital, 2011).

1.1 Haydom Lutheran Hospital

The idea for the study began at the Haydom Lutheran Hospital. Opened in 1955, the 400-bed Hospital is located 150 km south of the Ngorongoro Crater. The hospital is both owned and run by the Mbulu Diocese of the Evangelical Lutheran Church of Tanzania, however also receives aid from the government of Norway (Website of Haydom Lutheran Hospital, 2011). At the time this study was conducted Dr E. Olsen held the office as the director of HLH.

The hospital serves three districts out of the Manyara region (Mbulu, Hanang, Babati), and two districts out of the Singida region (Iramba, Ikungi). Furthermore, patients from the districts of Karatu, Ngorongoro, and Meatu are registered with the hospital.

Affiliated with the HLH is the Haydom school of nursing, which was founded in 1984 (Website of Haydom Lutheran Hospital, 2011).

Unlike many other rural hospitals, the HLH has comparatively better facilities and a more precise documentation system. Moreover, the hospital's departments for surgery, gynaecology and maternity, paediatrics, internal medicine, psychiatry, HIV, and diabetes are all equipped to a satisfactory level. X-ray, CT, EEG, and several sonography devices are also available, along with an electrical power supply backed by a generator. The hospital documentation system is comparatively precise. Further features of the HLH are an extensive Outpatients Department, a Dental Clinic and a Department for Physiotherapy. The hospital offers Internet access and a well-stocked library for all of its health personnel.

In 2009 alone over 15,000 patients were admitted to the wards, with an average stay of 6.2 days (Website of Haydom Lutheran Hospital, 2011). This was an increase from 12,060 patients in 2004 (Haydom Annual report, 2005). Among the most prevalent reasons for an admission were in 2004: spontaneous vaginal delivery, malaria and pneumonia. 79,077

patients were treated in the Outpatient Department in 2004, mostly because of malaria, pneumonia and epilepsy at the third rank (Haydom Annual Report, 2005).

1.2 Haydom Lutheran Epilepsy Clinic

Due to the prevalence and impact of epilepsy within the catchment area of the hospital, it became apparent that a specialised treatment was much-needed. As such in 2002 Dr A. Winkler planned and founded the Haydom Lutheran Epilepsy Clinic.

The Clinic was to be formed and staffs were allocated to the clinic. Personnel were trained in the diagnosis, treatment, and management of epilepsy patients. Starting out the clinic consisted of Nurse Michaeli Ombay alone together with Dr Winkler. Later they were joined by Nurse Bartholomayo Mathias in order to better cope with the increasing number of patients.

The Finnish Christian Medical Society and the Savoy Epilepsy Foundation from Canada agreed to finance the supply of medication that should be free of charge for the patients. Phenobarbital and carbamazepine are available in Tanzania. Valproic acid is to be used as reserve medication only, as it needs to be supplied from abroad which completely relied on private donations.

The first patients were recruited among the hospital inpatients, admitted for severe recurrent seizures. Further patients were recruited during the epidemiological study on neurological diseases done by three medical students from Germany and Austria, which started in November 2003 (Winkler et al., 2009). The biggest contribution, however, was achieved by referrals from word to mouth, after the clinic became well-known in the area around Haydom.

To ensure an optimum treatment of the patients standardised guidelines were created consisting of three columns: a) Classification of the seizures. b) Algorithms for drug treatment to show the exact indication, dosage, and side-effect profile of each drug. c) Information for patients and family about the disease, the drugs to be taken, mainly side effects and importance of compliance, social reintegration and special precautions for epilepsy patients (information after personal communication with Dr Winkler).

Despite the resource-poor setting of Haydom, continuous supervision of the assessment of new patients, as well as follow-ups by Dr Winkler over a two-year period, allowed the two clinical officers to become specialists in diagnosing, treating, and managing epilepsy. Because of this, in 2004 when Dr Winkler left Haydom the responsibility of the clinic could

be effectively handed over to local medical staff under the supervision of clinical officers Michaeli Ombay and Bartholomayo Mathias. At the time of the hand-over there were about 400 patients registered.

As evidenced by register-card and the daily showing up of patients, the clinic continued to be properly maintained. In 2007 over 500 patients were registered and yet another nurse enlisted for collaboration.

2 BASIC FACTS OF TANZANIA

The United Republic of Tanzania was founded in 1964 after achieving independence from Britain in 1961. The islands of Zanzibar were united with the mainland. Since 2000 Tanzania together with Burundi, Kenya, Rwanda and Uganda form the East African Community (East African Community, 2013) as the greatest of these countries with an area of 945,087 sq.km (Gabriel, 2003).

The official language in Tanzania is Kiswahili. English is the official primary language of commerce and administration (CIA, 2012). There are more than 130 spoken local and tribal languages, corresponding to more than 130 tribes that are registered in Tanzania, of which about 95 per cent are Bantu-tribes, followed by the Nilotes, Cushites and Khoisan (Gabriel, 2003).

In 2006 Tanzania had a population of 37.9 million people (Tanzania e-Government Agency, 2013) with a growth rate of 2.09 per cent per annum (Index Mundi - Country Facts, 2013). The Fertility rate in 2004 was 5.7 children per woman. Also, migration has shown a big impact on population growth, particularly in areas receiving refugees (Tanzania e-Government Agency, 2013).

The majority of the population (77 per cent of all Tanzanians) still lives in rural areas.

Life expectancy at birth was in mean 50.7 years in 2007 and the infant mortality rate was 71.7 per 1,000 live births in 2007 (Index Mundi - Country Facts, 2013).

The 1971 Marriage Act declared a legal minimum age of marriage of 15 years for females and 18 for males (Emory law, 2012).

Concerning polygamy, the legal position is verbatim: *"Polygamy is permitted with consent of first wife; upon registration, parties are to declare whether marriage is polygamous, potentially polygamous, or monogamous, and marriage may be 'converted' to polygamous or monogamous by joint declaration."* (Emory law, 2012).

Since the independence (when illiteracy rate was about 70 per cent) the Tanzanian government achieved great success in expanding education. Since then, the literacy rate increased up to 73 per cent between 2005 and 2010 (UNICEF, 2013). The remaining illiterates found in the population are 22 per cent male, 38 per cent female. But in some remote regions especially where people are occupied with agriculture only, illiteracy was still about 82 per cent (State University, 2007).

Tanzania ranks among the poorest countries of the world. 200-2009 about 68 per cent of the population lived below the international poverty line of US$ 1.25 per day (UNICEF, 2009). The gross national product was US$ 410 per capita in 2007 (Index Mundi - Country

Facts, 2013). Labour force - by occupation - was estimated in 2002: agriculture: 80 per cent; industry and services: 20 per cent (CIA, 2012).
Still, in a region faced with political instability and conflicts, Tanzania remains one of the more peaceful countries of Africa (United Nations Public Administration Network, 2004).

2.1 Administrative system

Tanzania is a republic based on a multiparty parliamentary democracy.
Presently, there are 25 Regions, 132 Districts and 516 Divisions on the Mainland Tanzania (Prime Minister's Office of The United Republic of Tanzania, 2009).
Divisions are divided into wards and every ward is partitioned several villages, those again in subvillages.
The subvillages previously consisted in ten-cells, which means that one ten-cell is formed by approximately 10 households, each having a leader. Since introduction of the multiparty system, the ten-cell isn't part of the official administrative system anymore but is still generally accepted and realized (Grawert, 2009).
Thus, the study at hand had it base on the HLH, situated in Manyara region, Mbulu and Hanang district, Dongobesh and Bassotu Division, Haydom Ward, Haydom village.

2.2 Health care system

The health system is under state supervision and as strictly hierarchically structured as the administrative system is (Tanzania e-Government Agency, 2009).

Village health service

The lowest level of health care delivery in the country, that provides preventive services also offered in homes. Usually two village health workers chosen by the village government amongst the villagers serve at these health posts after a short training period.

Dispensary Services:

There are 4940 dispensaries in the country. A dispensary caters for between 6,000 and 10,000 people and supervises all the village health posts in its ward. The ownership is mostly governmental (about 70 per cent of all dispensaries), followed by private (16 per cent) and faith based institutions (13 per cent).

Health centre services

A health Centre is expected to cater for 50,000 people which is approximately the population of one administrative division.

District hospitals

Each of the 132 districts is supposed to have a district hospital. Government often negotiates with religious organizations to designate voluntary hospitals or get subventions from the Government to contract terms.

Regional hospitals

Regional Hospital offer similar services like those agreed at district level, however regional hospitals have specialists in various fields and offer additional services which are not provided at district hospitals.

Referral/consultant hospitals

This is the highest level of hospital services in the country presently there are four referral hospitals namely, the Muhimbili National Hospital serving the eastern zone; Kilimanjaro Christian Medical Centre for the northern zone, Bugando Hospital for the western zone; and Mbeya Hospital which serves the southern Highlands.

Treatment abroad

Depending on the foreign exchange position, some patients should be sent for treatment abroad, when diseases and cases require special treatment whose facilities and equipment are not available in the country (Tanzania e-Government Agency, 2009).

3 STUDY POPULATION AND SAMPLING

Within two years of establishing the Haydom Lutheran Epilepsy Clinic genuine epilepsy was diagnosed in 337 patients. These were the first patients registered within the Haydom Lutheran Epilepsy Clinic. The demographics and social characteristics of these PWE were evaluated and analysed in a former study (Schaffert, 2005). From now this group will be termed "*source population*", to avoid misunderstanding.

The average age of the source population was 21.6±15.6 years; male/female ratio was almost equal at 1.08. Patients with generalised epilepsy numbered 206 (61.1 per cent), 102 (30.3 per cent) had focal (partial) epilepsy, 29 (8.6 per cent) patients had other types of seizures (Schaffert, 2005).

All patients of the source population were determined to be eligible for the study population of the planned study. All were formally examined and diagnosed by neurologist Dr Andrea Winkler and as they had already been examined in a previous study basic information about the patients was available.

3.1 Tribes

Tanzania is estimated to have a total of 125-130 ethnic groups, falling mainly into the four categories of Bantu, Cushitic, Nilotic and Khoisan (Wessendorf, 2008).
The biggest part of the examined sample was 73.8 per cent (90/122) of Iraqw-people. Iraqw are a Cushitic tribe solely settling the Arusha and Manyara regions of north-central Tanzania, near the Rift Valley wall and south of Ngorongoro Crater. In 2001 the total Iraqw population was estimated to count 462,000 people (Lewis, 2009).
Second most were Datoga with 16.4 per cent (20/122) representatives. The Datoga are a pastoralist Nilotic tribe of north-central Tanzania (Singida and Manyara regions; Mara region, Bunda and Serengeti districts). In 2000 the Datoga population was estimated to be 87,978 (Wessendorf, 2008). Iramba participated with 4.1 per cent (5/122). They are natives of Iramba, one of the four districts of the Singida Region bordering in the north-east to the Manyara Region (Wessendorf, 2008). 1.6 per cent (2/122) were members of Niaturu, belonging to a Bantu tribe based in the Singida Region of north-central Tanzania. In 1993 the Niaturu population was estimated to be 556,000 (Wessendorf, 2008). The remaining participants belonged to other Bantu tribes.

3.2 Sampling

The PWE were divided in groups of «Attenders» and «Non-Attenders» with help of register cards. Those who had shown up at least once within the last twelve months (i.e. September 1, 2006 – September 1, 2007) were classified as Attenders; failing to do so resulted in the patient being categorised as Non-Attender. In addition to this, the case of every patient was discussed with the nurses of the Haydom Lutheran Epilepsy Clinic to avoid misunderstanding of the register-cards. Each contact with the Epilepsy Clinic counted, including, if it was a relative who picked up the medication for the patient and gave a report of the state of the patient's health.

According to above procedure 188/337 (55.8 per cent) patients were pre-identified as Non-Attenders and 149/337 (44.2 per cent) as Attenders.

In practice, appointments had been given adapted to the severity of the course of epilepsy. This leads to some cases for which further contemplation is needed.
The "borderline cases" were as follows: There were two Non-Attenders outstanding who claimed only having missed occasionally an appointment, respectively two other Non-Attenders who missed less than half of the appointments. They had but not been to the Haydom Lutheran Epilepsy Clinic for more than 12 months. Appointments for these patients had been given in broader intervals, however, these four patients also had never shown up for picking up medication. After closer inspection and advised by the nurses, they were classified according to the mentioned definition as Non-Attenders.
On the other hand, one Attender having missed more than half of the appointments per year was (after consultation with the responsible nurse) classified as Attender as he had been to the Haydom Lutheran Epilepsy Clinic within the last twelve months.
As a sole exception of the classification, one patient, who had not been to the hospital for over one year was classified as "Attender". As a relative to one of the nurses working at the Haydom Lutheran Epilepsy Clinic, it could be ensured that this patient was monitored and treated with medication regularly. For this reason, she was considered to be an "Attender". For further information see chapter Results (III.9.1; page 93f).

The initial aim of study was to meet all 337 PWE of the source population within a time frame of five months. After consulting several people with a good knowledge of the region it was agreed upon that this would not be a sufficient amount of time. The number needed to be diminished.

A rigorous approach was taken in order to avoid bias. Each PWE was sorted according to their district, division, village, and sub-village. Next, several villages, chosen randomly out of the divisions, were excluded. This resulted in a sample of almost 200 patients. The selected villages are listed in Table 2.

Table 2: Selected villages in which the study took place

Manyara region	Singida region
Babati	Gajaroda
Bassotu	Iramba
Dirim	Kidarafa
Dongobesh	Mwanga
Dumbeta	Mwangeza
Endamilay	Singida village
Endanachan	
Getanyamba	
Getarer	
Gidika	
Hanang	
Harar	
Haydom	
Katesh	
Labay	
Laghanga	
Maghang	
Mbulu	
Measkron	
Mewadan	
Mogitu	
Mulbadaw	
Ng'wandakw	
Qamatamanat	
Riroda	
Tlawi	
Ufana	
Yaeda Ampa	

Throughout the course of collecting data, a premature wet season meant that visits to some areas had to be delayed. During this period of the time previously visited villages close to moderately far from Haydon were visited. So as not to bias the data, it was in eight cases decided randomly before starting in the morning which one of 3-6 subvillages we were up to visit, was omitted.

For patients who could not be visited and interviewed due to time constraints and various other reasons, it was discussed with the nurses of the Haydom Lutheran Epilepsy Clinic, if each of these patients was to be classified as Attender or Non-Attender.

The scheme in diagram 2 shows the distribution of the 337 PWE mentioned before.

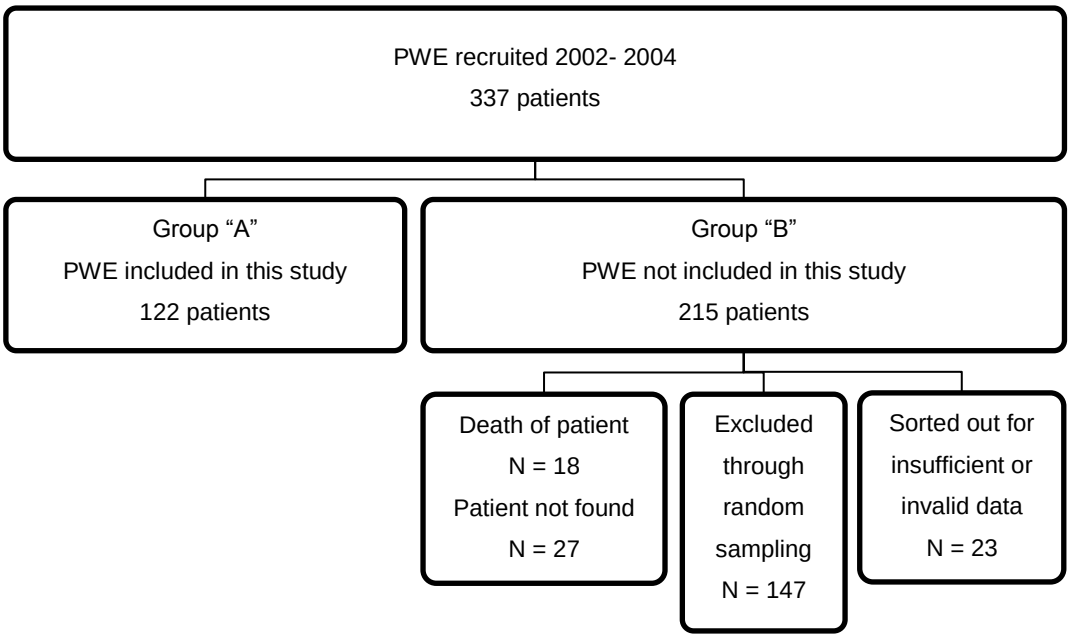

Figure 3: Distribution of the patients and group-forming

A significant difference between the patients included in this study (Group A) and those not included (Group B) arose in the distance they had to overcome to reach Haydom ($p = 0.01$). The travel required by patients in Group A was on average approximately 10km less than their counterparts in Group B.

The number of people who had experience in the application of herbal treatments also differed significantly ($p = 0.05$). There were more people in Group A (62/122 patients; 50.8 per cent) who affirmed to having tried herbal treatments in order to cure epilepsy, as opposed to 86/215 (40.0 per cent) patients in Group B. For further discussion on this issue see chapter Discussion (IV.5.5; page 140).

An overview of other compared variables between Group A and B is shown in Table 3.

Table 3: Differences of the chosen variables between interviewed PWE and those not interviewed as outlined in figure3

Item	Group A vs. Group B
Continuous Data	p
Avg. frequency of fits before treatment	0.45
Avg. frequency of fits after current treatment	0.42
Age at first fit	0.84
Time from first seizure to clinical presentation (yrs.)	0.66
Number of own children	0.55
Distance to hospital (km)	0.01
Number of cows	0.31
Number of goats	0.14
Age started drinking	0.36
Drunk days per week	0.85
Categorical Data	p
Gender	0.14
Tribe	0.72
Marital Status	0.29
Religion	0.64
Occupation	0.25
Diagnosis	0.10
Diagnosis group	0.76
Mental retardation	0.22
Type of current antiepileptic drug	0.94
Reduction of fit frequency (gradational)	0.09
Satisfactory response	0.11
Side effects	0.72
Herbal Treatment	0.05
Reduction of fits on H.T.	0.42
Scarifications	0.24
Educational level	0.06
Attendance at school	0.07
Type of house	0.59
Economic status	0.40
Alcohol consumption	0.33

Description of the source population

After founding the Haydom Lutheran Epilepsy Clinic during several prolonged stays Dr. Andrea Winkler, supported by a couple of students, identified and registered 346 patients of whom 337 suffered from genuine epilepsy.

This group was monitored by Dr. Winkler between 2004 and 2007 and there were regular follow-up exams conducted among the patients. Treatment-adherence was observed and described over this period of time.

On the one hand we used information from this source to complete our data (i.e. the thoroughly made diagnosis), and furthermore the earlier monitored group was adduced to predict the adherence behavior.

4 STUDY DESIGN

4.1 Planning

Whilst revisiting the Haydom Lutheran Epilepsy Clinic in 2005 and 2006, two years after it was first established, Dr Andrea Winkler noticed that a considerable number of patients were failing to attend their follow-ups. Questions arose as to what, despite good treatment outcomes, led to this behaviour of the PWE; and how they could be supported in order to keep regular appointments.

A cross-sectional, case-control study was therefore planned from the summer of 2006 onwards. It was hypothesised that there were differences between those who visited the clinic regularly and those who did not. The study sought to identify what these might be.

In August 2007 a research proposal and the study itself were approved by the Ethics Committee of the National Institute of Medical Research (NIMR) and the Tanzanian Commission for Science and Technology (COSTECH), both of which are located in Dar es Salam. Furthermore, permission for conducting this study was verbally obtained from the medical management of the HLH.

4.2 Design of questionnaire

The most important research tool of the present study was a standardised questionnaire (see Appendix), based on one that was used and developed by Dr Andrea Winkler during her stay at the HLH from July 2002 to November 2004. There it proved itself to be reliable and valid especially for use in a rural African area.

The questionnaire was expanded to include questions concerning reasons for not attending the clinic, alcohol-consumption as well as a special emphasis on psychosocial terms. The screening question was whether or not the patient had visited the Haydom Lutheran Epilepsy Clinic within the last 12 months. In this regard the answers given by the patients were very mostly consistent with the data of the register cards.

Regarding the applicability of questions to the age of the patients, I was counselled by an experienced neuropsychologist. Involved were particularly the parts ‘social aspects’ and ‘use of health care service’. In detailed discussions the respective age, a child could apprehend a question, was agreed on. The restrictions are specified at the beginning of the according paragraphs within the chapter results.

Questions not explicitly concerning the patients‘ individual opinion or feeling, but concerning facts were addressed to the main carer (thus normally to parents).

The structure of the questionnaire:

The first part of the questionnaire contained questions regarding the demographics of the patient, such as name, age, gender, tribe, religion, marital status and occupation, address including distance to the hospital, means of transport to Haydom, and travel time to reach the hospital.

The second part was about medical history and attendance at HLH: Seizure history (description of seizure, age at first seizure, current frequency of seizures, and the frequency before treatment), treatment history (current use of anti-epileptic medication, type of drug(s) being taken, reason not to take the drugs), adherence to the HLH (reason for last visit, reason not to come, treatment at a dispensary).

Part three was widely extended and included questions about education (attendance regular or attendance at all, when started, currently in school, level, reason not to visit school) and social status (number of children, age at marriage, age of spouse, practice of polygamy, marital problems, reasons to stay unmarried (if applicable), number of cohabitants, problems with living together, financial situation, physical independence (see below), main-carer for the patient, patient’s situation within community, his/her work performance and role in domestic life, existence of a social network, outside knowledge of the patient’s suffering from epilepsy, how the patient copes with epilepsy, and if he/she had a sensation of debasement and/or prejudice against him/her. Also asked was whether or not there was ever aggressive behaviour directed at the patient, particularly insults, physical violence or abuse.) Questions pertaining to the economic status of the patient were also asked in part three (e.g. food security (see below), defecation management, water-supply, number of cattle, and number of transport-medium).

Part four dealt with healthcare in general and the use of traditional treatment, as well as the patient’s perception of epilepsy.

Part five consisted of questions concerning drinking habits, whilst in part six the results of the physical-neurological examination and impression of the mental status were noted. The neurological examination involved the testing of cranial nerves, motor skills, tone and reflexes as well as sensation.

Explanations concerning part three of the questionnaire: Concerning financial and physical dependence this item aimed to detect the dimensions in which patients depended on favourers (who were essentially family members). Financial dependence excluded children under the age of sixteen, as from this age on they were able to financially contribute to the family budget. The other item involved a physical dependence of the patient, such as being fed, washed, swaddled, etc. This sub-item was split in light physical dependence on the one hand (excluding children under age eight, as from that age on normally a child can care physically for themselves), and on the other by intensive physical dependence (excluding children under the age of three who inherently need help and comprehensive care involving various tasks).

Due to concerns about food security, patients were asked about the regularity of their meals and how often any had to be skipped as a result of food shortages. A designation of «very poor» meant that there was often just one ordinary meal consumed per day and/or more than three meals per week skipped. «Poor» meant that 1-3 meals per week were skipped on a regular basis, whilst «regular» meant that meals were seldom skipped and two or three standard meals per day were the norm. «Good» food security indicated that there was sufficient food on a day to day basis, and also enough to create a food reserve. «Very good» meant there was no trouble at all with their food supply and that they even had a significant amount of edibles disposable to them.

4.3 Classification of epileptic seizures

The classification of different types of seizures is necessary for the adequate treatment, the prescription of medication, and to estimate the course of the disease.

The study adopted the diagnoses of experienced neurologist Dr A. Winkler, which were already used during the study's pre-evaluation period. Epileptic events were grouped according to a highly effective classification developed by Dr Winkler for developing countries (Winkler et al., 2007).

1) Generalised seizures:

• Primary (idiopathic) generalised epilepsies or idiopathic epilepsies with age related onset: epilepsies that start within a specific age group (mainly between the ages of six to 20-25), where there is no obvious cause and no brain damage, but where there may be a positive family history and a genetic cause for these.

• Generalised epilepsies without brain damage: these lie outside the specific age group of the primary generalised epilepsies but have no focal start and no clinical sign of brain damage. There may be a cause which cannot be diagnosed with the currently available medical technology, thus these seizures may be “cryptogenic”.

2) Partial (focal)

• Generalised seizures with brain damage: clinically brain damage is present and a cause may be obvious. All age groups can be affected but there tends to be a shift to the younger ages.

• Secondary generalised epilepsies: generalised seizures with a focal start or clear unilateral seizures, but without obvious cause or major brain damage. There may be developmental delay or subtle signs of brain damage. All age groups can be affected.

• Complex partial seizures: characterised by impaired consciousness without generalised tonic-clonic activity. The two essential features are partial or complete lack of awareness and amnesia for the event.

• Simple partial seizures: no impairment of consciousness and motor, sensory, visual, auditory, olfactory, automatic or psychic origin. Epileptic aura: the first clinical signs of a seizure with a highly localising value. It results from the anatomical or functional neuronal activation of part of one hemisphere.

3) Other types of seizures:

• Pseudoseizures or psychogenic seizures: resemble epileptic seizures. Patients experience episodes of loss of consciousness, twitching or jerking, and unusual emotional states, such as intense feelings of fear or déjà vu. The episodes may last 20 minutes, but are not associated with electrical abnormalities in the brain as is the case with epileptic seizures.

• Two different seizure types: like simple partial, secondary generalized seizures, primary generalised seizures, pseudoseizures etc.

• Unclassified epileptic seizures: include all those seizures that cannot be classified because of inadequate or incomplete data.

(Winkler et al., 2007)

5 DATA COLLECTION

5.1 Preparation

After the study sample was determined, the questionnaire and translator were approved during a pilot phase. Following this, the actual study could be conducted between the beginning of September 2007 and Mid-January 2008. A total number of 145 interviews were conducted, of which 23 were separated out for insufficient or invalid data and 122 were deemed to be valid as per the defined criteria, and included in the analysis. For the complete distribution, see figure 3, page 30.

Andreas Kampmann and I, both final year students at the University of Ulm, Germany, acted as interviewers. During this period, A. Kampmann had conducted another study at the Haydom Lutheran Epilepsy Clinic which compared EEG-results with computer tomography-findings of PWE.

In a pilot phase the operation in conducting interviews was adjusted between me and A. Kampmann. He then conducted approximately 20 interviews at the HLH with patients who appeared for regular appointments. Occasionally he also went out field-interviewing.

The screen test for alcohol consumption failed (Michigan Alcohol Screening Test; by Hodgson et al., 2002) as it was not practical, and so the test was excluded. Questions concerning alcohol consumption were reduced and simplified.

Lists of the chosen villages and sub-villages, and the inhabitant patients were copied and distributed to the team members; consisting of two interviewers, two interpreters, and two medical officers. These lists were regularly updated and rearranged, so everyone was aware of which patients were still missing. This was important therefore the progress of the study could be accelerated when chosen Attenders visiting the Haydom Lutheran Epilepsy Clinic were identified and interviewed inside of HLH respectively a new appointment was given to them for interview.

The very predominantly involved interpreter was Jovita H. Daniel, a secondary school graduate. He had previous experience having already participated in earlier projects. Nevertheless, he was retrained as a part of the testing-phase. The course of the study benefitted greatly from him being able to speak fluent English, Kiswahili, and two prevalent tribal languages (Iraqw and Datoga). His knowledge of the study area (in particular the ability to plan routes), customs, and culture were of great help.

Michaeli Ombay and Bartholomayo Mathias are two medical officers running the Haydom Lutheran Epilepsy Clinic. They continued their regular activity at the Haydom Lutheran Epilepsy Clinic and assisted additionally by identifying patients, confirming appointments, and providing general information about patients and the Haydom Lutheran Epilepsy Clinic to the interviewers.

5.2 Field work

After reaching a relevant sub-village (generally via four-wheel drive, or bike or foot in the case of nearby sub-villages), the responsible «ten-cell leaders», who act as the administrative leaders for a group of approximately 10 households, were contacted. The study and its objectives were explained, and permission was asked to carry out the interviews, which it was given in each case.

Thanks to the ten-cell leaders we could find the houses that were mostly widespread within the territory (the area is not populated densely). When the desired PWE were found, and after they agreed to participate, the patients were asked questions from the questionnaire in the presence of their relatives, and subsequently they were physically examined.

When a patient was interviewed at the HLH no ten-cell-leader would be involved, instead they agreed to participate themselves.

In patients who could only respond partially or not at all, particularly little children, high aged or handicapped patients and mute patients, the close relatives or main carers answered instead. Questions concerning perception of epilepsy were omitted in children or in patients who were unable to form an opinion.

If a patient was not met at home up to three field-revisits (depending on how far away the patient lived) would be undertaken, especially when people in the neighbourhood indicated that they would return soon.

Fifteen patients moved far from the catchment area, and thus could not be interviewed, and 12 were either not found or met (one young patient was in college in Dodoma at this time and therefore could not be surveyed, 11 patients could not be met even after re-visits or did not show up for appointed interview inside HLH and thus could not be interviewed). The population is, by European standards, a relatively mobile one. As such about twenty more patients had moved since registration, but were able to be found later after exact

description of the new place by ten-cell-leaders or relatives. Marriage also was a common reason to relocate.

Following the advice of the interpreter, who was present during the preparation of the data collection, it was decided to clear first those villages which were most remote and far away.

This turned out as an advantageous proceeding for the second rainy season arrived quite early in that year and became particularly noticeable from the end of October 2007 on. Still we could reach villages per four-wheel drives, however it became increasingly laborious and the number of interviewed patients decreased to just two persons on some days. Fortunately, by mid-November the distances to the quested villages could be overcome by bicycle. Villages within the direct surroundings of Haydom could still be visited then.

6 DATA ANALYSIS

The data was collected in Tanzania, then tabulated on-site into Microsoft Excel 2000 and subsequently transferred into SPSS 12.0 (Statistical Package of Social Sciences) after returning to Germany.

Formerly collected data of the source population was handed out by Matthias Schaffert, who had collected it during 2002 and 2004 in collaboration with Dr Andrea Winkler. This collection included data of the above mentioned 337 PWE, of which 122 patients were included into the current study (figure 3).

By means of the SPSS, statistical calculations and most of the diagrams were made. A few of the diagrams and all the charts were made in Microsoft Excel 2000.

In terms of statistics "*Basiswissen Medizinische Statistik*" (Weiß, 2008) was mostly used as reference book.

Statistical analysis in detail

The data was sorted in categorical data (consisting of a countable amount of values, e.g. different tribes) and continuous data (consisting of a theoretically uncountable number of values of which means can be calculated. e.g. number of seizures).

Before in continuous data the mean, the standard-deviation (SD) and the median were computed, the Kolmogorov-Smirnov test was used to determine whether or not the data was evenly distributed.

The data in this project was generally distributed unequally (synonymous: asymmetrically or non-parametric), except for the item "age at marriage". Only at this item the t-test was applied.

For the other items of continuous data, the Mann-Whitney U test was used to calculate the statistical relevance of a difference between the two groups.

This kind of test is a non-parametric test of the null hypothesis that two populations are the same against an alternative hypothesis. It has greater efficiency than the t-test on non-normal distributions, such as a mixture of normal distributions, and it is nearly as efficient as the t-test on normal distributions.

In non-parametric data the mean and the SD can be calculated, but they might give a wrong impression of the data; as there are several outliers. If so, a box-and-whisker-plot can be useful to display the distribution. An example of this kind of plot is shown in diagram 3. The box represents the inter-quartile range (IQR), i.e. the range in which 50 per cent of the sample values are. The cross bar in the box is the median, which is in this case more important than the mean (not painted), as its position helps with understanding the distribution. The whiskers comprise all data from the lowest to the highest value within 1.5 times of the inter-quartile range. The squiggles mark a value between the 1.5- and 3-times of the inter-quartile range (suspected outlier) and asterisks represent a real outlier, which is more than 3-times that of an IQR. This kind of plot can also be used for parametric data, as it often visualises the values better.

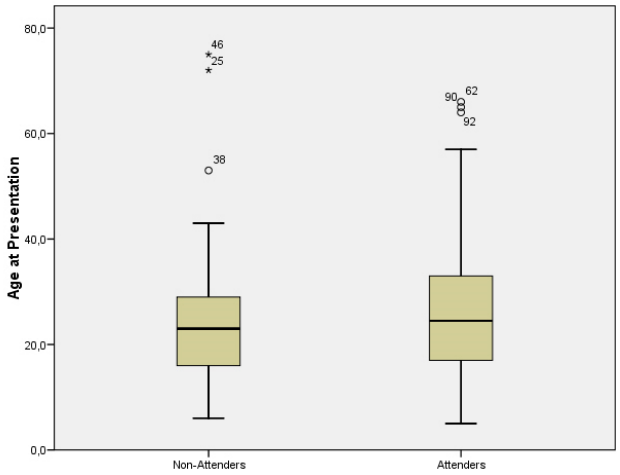

Figure 4: Example for a box and whisker plot

Tests in categorical data were the Pearson Chi-Square (χ^2) test and the Fisher's exact test.

The χ^2-test is used to determine the probability that two variables are independent from each other and if it is likely that the distribution of values found in the sample group can be assumed to account for the general population. Therefore, if the χ^2-test is, it can be assumed that there is a connection between the two variables examined and that it is likely (with a chance of 95 per cent) that the distribution found in the study population will be found in all people with the appropriate prerequisites.

Fisher's exact test is a variant of the χ^2-test, but more precise. It was applied when there was a value represented by less than five answers.

The significance level was set at ≤ 0.05 for all tests.

III RESULTS

The study population was chosen from the source population of 337 patients of which 122 were selected for the main analysis as reflected in the following results. For a description of the patients not included in these results see methods (II.3.2; page 30 ff).
Thus, the 122 patients participating in the main case study were selected from those who were interviewed, examined and diagnosed by Dr Winkler between 2002 and 2004, and whose paper index files were on file at the Haydom Lutheran Epilepsy Clinic. They were divided into two separate groups, Attenders and Non-Attenders. Inclusion/exclusion criteria for one or the other group are specified in methods (II.3.2; page 28). Applying the case definitions, 56 participants were classified as Non-Attenders and 66 patients as Attenders.
Each of the following subchapters will be preceded by a summary of the most important/significant results. In addition, there will be an overall summary of the statistically significant findings at the end of the chapter Results (III.13; page 121 f).

1 DEMOGRAPHIC AND OTHER CHARACTERISTICS OF THE POPULATION STUDY

The only statistical significant difference in the contents of the demographics was the distance to Haydom, which was longer for Non-Attenders than for Attenders.
Attenders were in average more than two years older than Non-Attenders and there were more ‘children’ amongst Non-Attenders, however concerning these differences a statistically difference was not found. The remaining items showed no outstanding discrepancies.

1.1 Age at presentation

The average age of the 122 participants was 25.7 (SD: 13.5; median: 23.0, range: 5-75) years. The mean age of Non-Attenders was 24.5 (SD: 13.4; median: 23.0, range 6-75) years, while it was 26.7 (SD: 13.7; median: 24.5, range 5 - 66) years for Attenders. No significance was determined, relative to these differences, in the Mann-Whitney U test ($p = 0.30$).

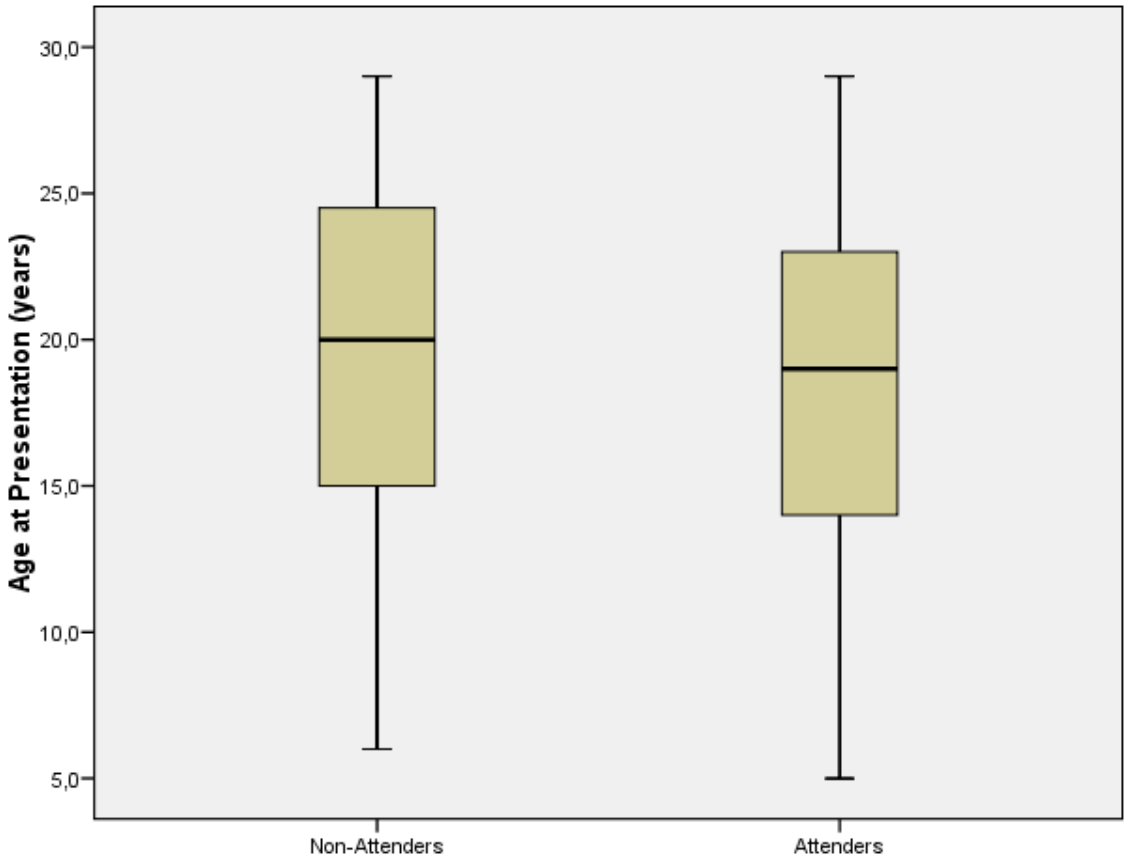

Figure 5: Age at presentation

Table 4: Age at presentation (yrs.)

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	24.5	13.4	23.0	6.0	75.0	56
Attender	26.7	13.7	24.5	5.0	66.0	66
Total	25.7	13.5	23.0	5.0	75.0	122

Mann-Whitney U	1628
Asymp. Sig. (2-tailed)	0.300

1.2 Gender

Overall, on a gender-ratio, males outnumbered females. From the 122 participants in the case study 44.3 per cent (54/122) were females and 55.7 per cent (68/122) were males.

Apparent in both groups was a slight preponderance of males, in Non-Attenders more than in Attenders. The Pearson Chi-square test found no significance concerning this difference (p = 0.513)

The percentage of male and female participants and their distribution can be observed in Table 5 and Figure 6

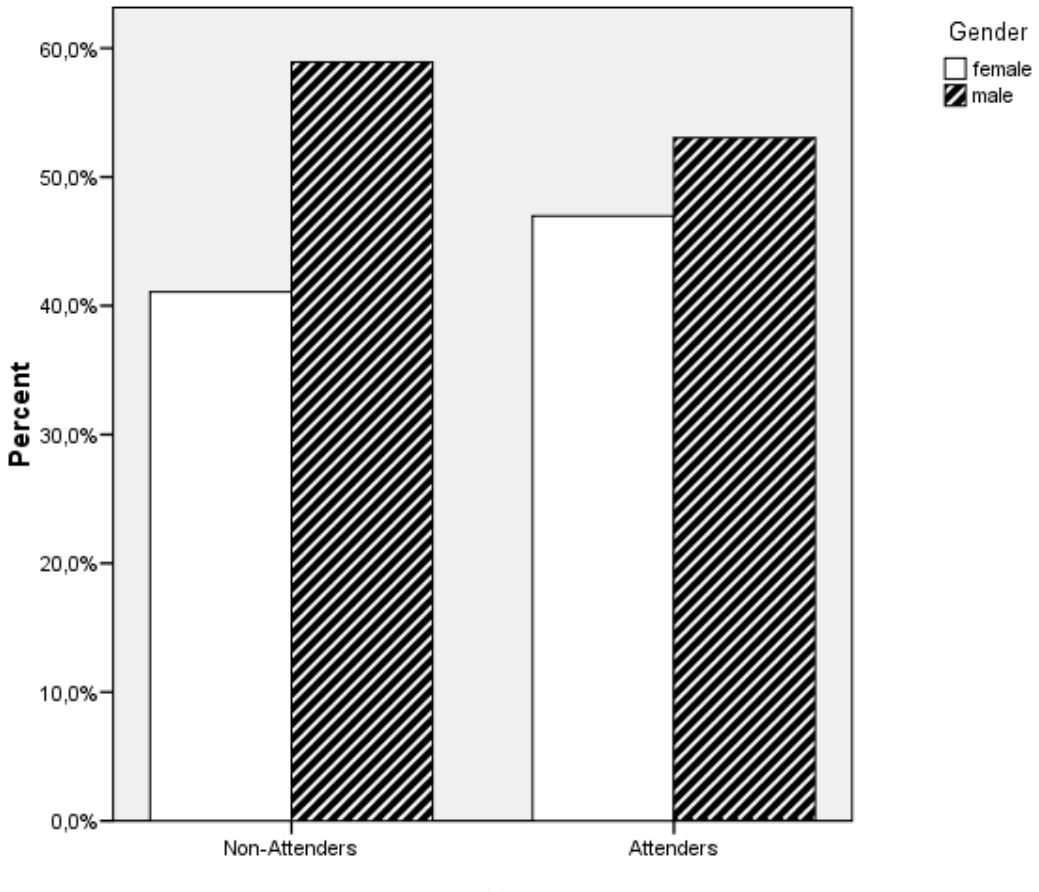

Figure 6: Gender

Table 5: Gender

	Non-Attender	Attender	Total
Female	23	31	54
	41.1%	47.0%	44.3%
Male	33	35	68
	58.9%	53.0%	55.7%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Asymp. Sig. (2-sided)
Pearson Chi-square	0.427	0.513
N of valid cases	122	

1.3 Tribe

The largest contingent of those participating in the case study, 73.8 per cent (90/122), was made up of the Iraqw-people, a Cushitic tribe settled in the Arusha and Manyara Regions of north-central Tanzania, near the Rift Valley wall and south of Ngorongoro Crate. The next group, with 16.4 per cent (20/122) of the participants was the Datoga, a pastoralist Nilotic tribe of north-central Tanzania. These were followed by the Iramba with 4.1 per cent (5/122) participating and the Niaturu, 1.6 per cent (2/122). They belong to a Bantu group residing in the Singida Region of north-central Tanzania. The remaining participants, 4.1 per cent (5/122), belonged to other Bantu tribes.

Regarding tribal members there were no noticeable differences between Non-Attenders and Attenders. Fisher's exact test also showed no significant discrepancies with $p = 0.730$.

Table 6: Tribe

Tribe	Non-Attender	Attender	Total
Iraqw	43	47	90
	76.8%	71.2%	73.8%
Datoga	8	12	20
	14.3%	18.2%	16.4%
Iramba	2	3	5
	3.6%	4.5%	4.1%
Niaturu	0	2	2
	0.0%	3.0%	1.6%
Other Bantu tribe	3	2	5
	5.4%	3.0%	4.1%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.34	0.730
N of valid cases	122	

1.4 Marital status

Persons up to their 18th birthday were labelled as "children" differentiating them from adult "single" persons. However, in this case study, there were four women who were already married before their 18th birthday.

With regard to family status, the greatest contingent consisted of 47.5 per cent (58/122) married individuals, followed by 31.1 per cent (38/122) children and 18.9 per cent (23/122) single persons. Two Non-Attenders were divorced from their partners and one woman (Attender) was separated.

Proportionally there were more "singles" in the Attenders group and more "children" among Non-Attenders.

Statistically this difference was not significant (Fisher's exact test – $p = 0.170$)

Table 7: Marital Status

	Non-Attender	Attender	Total
Child	20	18	38
	35.7%	27.3%	31.1%
Married	27	31	58
	48.2%	47.0%	47.5%
Single	7	16	23
	12.5%	24.2%	18.9%
Divorced	2	0	2
	3.6%	0.0%	1.6%
Separated	0	1	1
	0.0%	1.5%	0.8%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	5.65	0.170
N of valid cases	122	

1.5 Number of children

The information requested was the number of own children living and those who were deceased. Among the interviewed patients those under age of 16 (n=26) were excluded. Data of one male patient was not given for both items.

The mean number of their own children living was 2.26 (SD: 2.99; median: 1.0; range: 0-10) for Non-Attenders. Attenders had an average of 2.52 (SD: 3.15; median: 1.0; range: 0-12) children resulting in Non-Attenders having fewer children. This could be explained by the generally younger mean age of Non-Attenders (see chapter Results; III.1.1; page 44).

On average 0.44 (SD: 0.700; median: 0; range: 0-2) children of Non-Attenders and 0.58 (SD: 0.936; median: 0; range: 0-4) children of Attenders were deceased. This discrepancy in number could also be explained by the younger mean age of Non-Attenders.

In these comparisons there were no significant differences between Attenders and Non-Attenders (children alive: p = 0.874, children who died: p = 0.681).

Table 8: Number of own children alive*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	2.26	2.99	1.00	0	10	43
Attender	2.52	3.15	1.00	0	12	52
Total	2.40	3.10	1.00	0	12	95

	Number of own children
Mann-Whitney U	1098
Asymp. Sig. (2-tailed)	0.874

*One participant gave no answer; item was not applicable to 26 participants

Table 9: Number of children who died*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	0.440	0.700	0.0	0	2	43
Attender	0.580	0.936	0.0	0	4	52
Total	0.520	0.836	0.0	0	4	95

Mann-Whitney U	1072
Asymp. Sig. (2-tailed)	0.681

*Data of one participant is missing; item was not applicable to 26 participants

1.6 Religion

The most common religion was Lutheran with 42.6 per cent (52/122) being members. They are followed by 19.7 per cent (24/122) Catholics. The next group of 17.2 per cent (21/122) were Pentecostals, followed by pagans with 14.8 per cent (18/122). Muslims make up 0.8 per cent (1/122) of the population.

There was no significant difference between Attenders and Non-Attenders (p = 0.322 in Fisher's exact test).

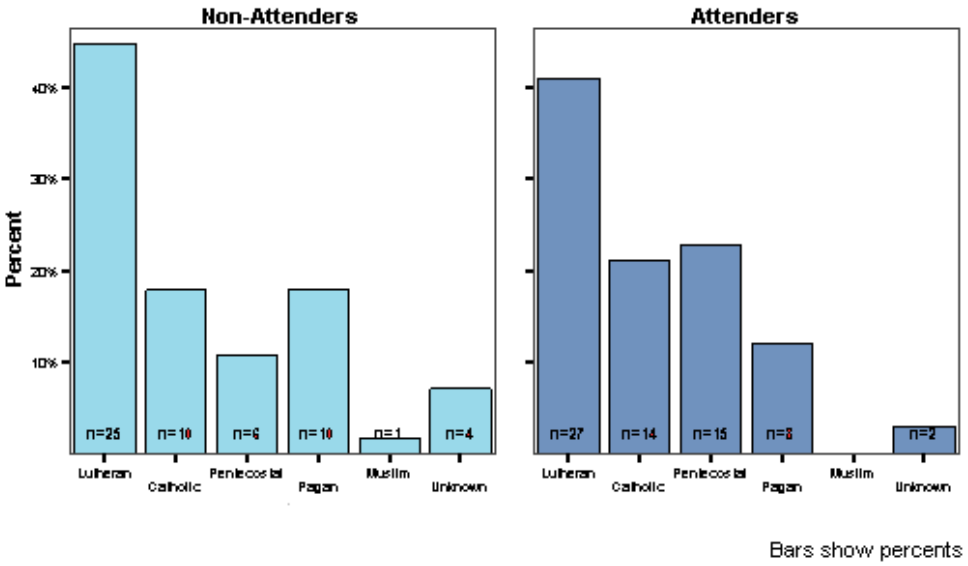

Figure 7: Religion

Table 10: Religion

	Non-Attender	Attender	Total
Lutheran	25	27	52
	44.6%	40.9%	42.6%
Catholic	10	14	24
	17.9%	21.2%	19.7%
Pentecostal	6	15	21
	10.7%	22.7%	17.2%
Pagan	10	8	18
	17.9%	12.1%	14.8%
Muslim	1	0	1
	1.8%	0.0%	0.8%
Not answered	4	2	6
	7.1%	3.0%	4.9%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	5.61	0.322
N of valid cases	122	

1.7 Occupation

Not surprisingly, due to their inherent determination, the greatest part, 63.9 per cent (78/122) of the participants answered proudly, that they were farmers and herdsmen. Proportionally the 65.2 per cent (43/66) of Attender farmers was slightly higher than the 62.5 per cent (35/56) of Non-Attender farmers. Labelled as children (up to 14th birthday, except those in group 'pupil') were 13.1 per cent (16/122) of the participants, of whom 13.6 per cent (9/66) were Attenders and 12.5 per cent (7/56) Non-Attenders. At the time of the interview, 9.8 per cent (12/122) were pupils and 1.6 per cent (2/122) students. 7.4 per cent (9/122) of the women identified themselves as being housewives. 3.3 per cent (4/122) of the participants described themselves as manual workers while 0.8 per cent (1/122) stated that he was a teacher.

There was no noticeable difference between both groups, confirmed by Fisher's exact test, $p = 0.905$.

Table 11: Occupation

	Non-Attender	Attender	Total
Farmer	35	43	78
	62.5%	65.2%	63.9%
Child (up to 14th birthday if not at school)	7	9	16
	12.5%	13.6%	13.1%
Pupil	7	5	12
	12.5%	7.6%	9.8%
Student	1	1	2
	1.8%	1.5%	1.6%
Manual worker	2	2	4
	3.6%	3.0%	3.3%
Teacher	1	0	1
	1.8%	0.0%	0.8%
Housewife	3	6	9
	5.4%	9.1%	7.4%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.92	0.905
N of valid cases	122	

1.8 Distance to Haydom Lutheran Hospital

The distance from home to HLH was less for Attenders than for Non-Attenders: The mean distance for Attenders was 30.3 (SD: 26.0; median: 25.0, range: 0-140) km, for Non-Attenders 41.3 (SD 29.6; median: 35, range: 0.5-130) km.

With p = 0.036 (by Mann-Whitney U test) this is a significant difference.

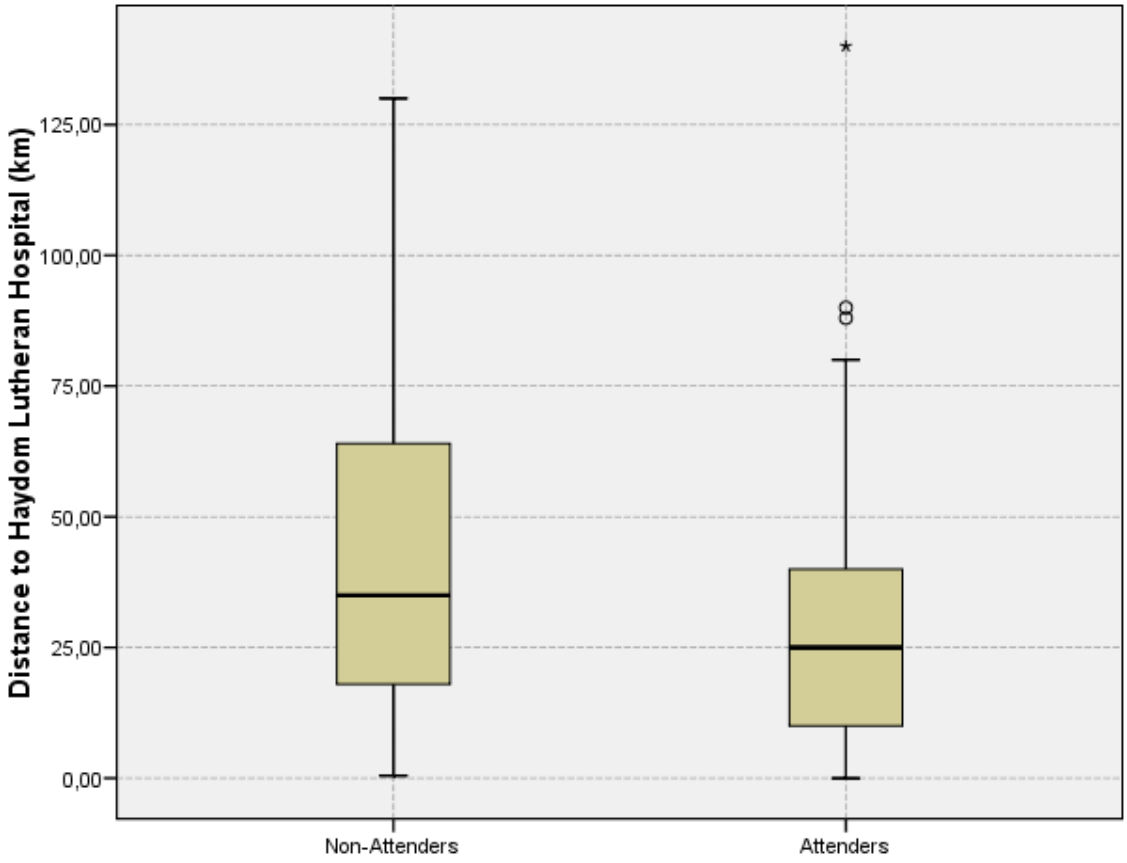

Figure 8: Distance to Haydom Lutheran Hospital (km)

Table 12: Distance to Haydom Lutheran Hospital (km)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	41.3	29.6	35.0	0.500	130	53
Attender	30.3	26.0	25.0	0.000	140	65
Total	35.2	28.1	27.5	0.000	140	118

Mann-Whitney U	1335
Asymp. Sig. (2-tailed)	0.036

*Four participants gave no answer.

1.9 Means of transportation to Haydom Lutheran Hospital

This item examined the question regarding which method of transportation was generally used to travel to HLH.

44.3 per cent (54/122) of the participants travelled to hospital by bus - divided up into 40.9 per cent (27/66) Attenders and 48.2 per cent (27/56) Non-Attenders.
Overall, 29.5 per cent (36/122) of the participants answered that they travelled on foot; 34.8 per cent (23/66). For Attenders it was the second most common way to travel to HLH. For Non-Attenders there were 23.2 per cent (13/56) who walked to the hospital.
Bicycles were the least used method of transportation. 19.7 per cent (24/122) of the participants answered so, of which 19.7 per cent (13/66) were Attenders and 19.6 per cent (11/56) were Non-Attenders.
6.6 per cent (8/122) of the participants didn't specify how they travelled to HLH.
The two groups differed in that, more Attenders travelled on foot compared to the majority of Non-Attenders who travelled by bus. Concerning this comparison of Non-Attenders and Attenders there was no significant difference found in Fisher's exact test (p = 0.451).

Table 13: Means of transport to Haydom

	Non-Attender	Attender	Total
On foot	13	23	36
	23.2%	34.8%	29.5%
By bus	27	27	54
	48.2%	40.9%	44.3%
By bike	11	13	24
	19.6%	19.7%	19.7%
Not answered	5	3	8
	8.9%	4.5%	6.6%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.65	0.451
N of valid cases	122	

1.10 Distance to the next dispensary

Twenty-two Attenders and 22 Non-Attenders were aware of a nearby dispensary, where a PWE could possibly get advice and/or AED. Some other patients lived close to the hospital and thus did not utilise the dispensary. Others were unaware of the whereabouts of a dispensary.
The distance to the next dispensary was greater for Non-Attenders than for Attenders. On an average Non-Attenders lived 11.0 (SD: 8.2; median: 10.0, range: 1-30) km and Attenders 9.41 (SD: 10.9; median: 5, range: 0-48) km away from a dispensary.

Table 14: Distance to next dispensary (km)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	11.0	8.19	10.0	1.00	30.0	22
Attender	9.41	10.9	5.00	0.00	48.0	22
Total	10.2	9.54	7.50	0.00	48.0	44

Mann-Whitney U	195.5
Asymp. Sig. (2-tailed)	0.272

*78 participants gave no answer

2 MORTALITY

In our study, within about three years there were confirmed deaths of 9.47 per cent (18 of 190 patients with confirmed epilepsy once registered in 2004). According to descriptions by relatives at least three of the patients died due to epilepsy (the causes of death of the other 15 patients remained unclear, no conclusive explanation was given by the relatives or the village people). Specified as Non-Attenders were 89 per cent (16/18), which accounts for a clearly higher mortality within this group. However, the method of chronological ranging was probably biased, as sometimes the date of death was not clear. Also, the sorrow and disappointment of a deceased PWE's relatives might have led to a disconnection to Haydom Lutheran Epilepsy Clinic and thus the death of a patient might not have been reported at times.
In any case, the number of dead patients is presumably underrated. Some of the Non-Attenders could not be met at their homes.

Because of the lack of sufficient information about the deceased patients and other insecurities, meaningful results of a calculation seemed to be impossible to get. Therefore, it was decided to forego further analysis.

3 DIAGNOSIS, SEIZURE AND TREATMENT HISTORY

In this subchapter it is noticeable that Non-Attenders were by far more often NOT on AED than Attenders. Those patients who were on treatment received drugs from the dispensary.

The diagnostic groups for the classification of epilepsy were used as allocated by Dr Andrea Winkler and outlined in the method section.

3.1 Diagnosis

The most frequent epilepsy diagnosis in both groups was “primary generalised epilepsy” totalling 54.9 per cent (67/122). 56.1 per cent (7/66) of them were Attenders and 53.6 per cent (30/56) were Non-Attenders.

All in all, “secondary generalised epilepsy” was the second most common diagnosis, this also applied to Non-Attenders. The frequency of “secondary generalised epilepsy” in Attenders resembled that of “two types of epilepsy” and “generalised epilepsy without brain damage”, followed in all groups by “generalised epilepsy with brain damage” and there was one patient (Non-Attender) with “Unclassified seizures”

The Fisher`s exact test found no significance in the difference of epilepsy diagnoses (p = 0.199).

Table 15: Diagnosis of epilepsy

	Non-Attender	Attender	Total
Generalised with brain damage	4	4	8
	7.1%	6.1%	6.6%
Generalised without brain damage	9	9	18
	16.1%	13.6%	14.8%
Primary generalised	30	37	67
	53.6%	56.1%	54.9%
Secondary generalised	11	8	19
	19.6%	12.1%	15.6%
Two types	1	8	9
	1.8%	12.1%	7.4%
Unclassified	1	0	1
	1.8%	0%	0.8%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	6.88	0.199
N of valid cases	122	

3.2 Age at first seizure

The difference between Attenders and Non-Attenders concerning their mean age at the first seizure was about one year. Attenders suffered from their first seizure aged 16.0 (SD: 13.8; median 14, range: 0-62) years on average, Non-Attenders aged 14.9 (SD: 13.7; median: 12.5 range: 0.5-70) years, the difference however was not significant (p = 0.736).

Table 16: Age at first seizure (yrs.)

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	14.9	13.7	12.5	0.50	70.0	56
Attender	16.0	13.8	14.0	0.10	62.0	66
Total	15.5	13.7	13.0	0.10	70.0	122

Mann-Whitney U	1783
Asymp. Sig. (2-tailed)	0.736

3.3 Average frequency of seizures before treatment (per month)

Before treatment and medication was started, Attenders reported that on an average, they had more seizures per month. Attenders suffered a mean of 17.0 (SD: 25.8; median: 7.5 range: 0-140) seizures per month and Non-Attenders a mean of 16.0 (SD: 29.4; median: 4.5; range: 0-150) seizures per month, however the difference was not significant in Mann-Whitney U test (p = 0.110).

Table 17: Average frequency of seizures (per month) before treatment*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	16.0	29.4	4.50	0.20	150.0	52
Attender	17.0	25.8	7.50	0.30	140.0	62
Total	16.5	27.4	5.00	0.20	150.0	114

Mann-Whitney U	1332
Asymp. Sig. (2-tailed)	0.110

*Eight participants gave no answer

3.4 Average current frequency of seizures (per month)

All participants were included, no matter whether or not they took drugs, or where they came from.

Attenders reported 2.0 (SD: 4.5; median: 0.5, range: 0 - 30) seizures per month and Non-Attenders reported 4.7 (SD: 21.3; median: 0.5, range: 0 - 150) per month. The difference was not significant in Mann-Whitney U test (p = 0.359).

Table 18: Average current frequency of seizures (per month)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	4.74	21.3	0.25	0	150	54
Attender	2.01	4.54	0.50	0	30	64
Total	3.26	14.8	0.50	0	150	118

Mann-Whitney U	1564
Asymp. Sig. (2-tailed)	0.359

*Four participants gave no answer

3.5 Use of anti-epileptic medication

Within the group of Attenders 90.9 per cent (60/66) were on AED. The remaining 9.1 per cent (6/66) were not on drugs for one of the following reasons. Four out of the six had no seizures over an extended term and were attempting to keep the seizures under control without the use of medication. One woman was pregnant and stopped treatment after medical advice. With one Attender the reason for not taking drugs was unclear. The difference between the groups was substantially significant.

Predominantly, 80.4 per cent (45/56) of Non-Attenders who were not currently taking AED, still 17.9 per cent (10/56) of Non-Attenders were receiving drugs from a dispensary (8/10) or some other non-specified location (2/10).

The difference accordingly was highly significant in Fisher's exact test: p~0.000.

Table 19: Use of antiepileptic medication

	Non-Attender	Attender	Total
No	45	6	51
	80.4%	9.1%	41.8%
Yes	10	60	70
	17.9%	90.9%	57.4%
Not answered	1	0	1
	1.8%	0.0%	0.8%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	72.0	0.000
N of valid cases	122	

3.6 Reasons for not taking anti-epileptic medication

If the patient was a child, the main carer was asked, why they had not given the medication.

The item was applicable to 51 participants who were not on medication at the time of the interview.

Most of the individuals, 54.9 per cent (28/51), answered (or were answered for) that they were no longer having fits. This answer was given by the majority of participants in both groups; 53.3 per cent (24/45) of Non-Attenders and 66.7 per cent (4/6) of Attenders.

'No response to drug' was received from 15.6 per cent (7/45) of Non-Attenders. Side effects of treatment were the reason that 2.2 per cent (1/45) of Non-Attenders discontinued treatment. None of these reasons applied to Attenders.

13.3 per cent (6/45) of Non-Attenders and 16.7 per cent (1/6) of Attenders gave alternative reasons.

The difference was not found significant in Fisher's exact test – $p = 0.929$.

Table 20: Reason for not taking anti-epileptic medication*

	Non-Attender	Attender	Total
No fits	24	4	28
	53.3%	66.7%	54.9%
No response	7	0	7
	15.6%	0.0%	13.7%
Other reason	6	1	7
	13.3%	16.7%	13.7%
Side effects	1	0	1
	2.2%	0.0%	2.0%
Not answered	7	1	8
	15.6%	16.7%	17.6%
Total	45	6	51
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	1.83	0.929
N of valid cases	52	

*This item was applicable to 51 participants who were not on medication.

3.7 Type of current anti-epileptic medication

Sixty Attenders and 10 Non-Attenders only were taking AED at the time of the interview.

CBZ clearly dominated, taken by 60.0 per cent (42/70) of the participants. For Non-Attenders this was the only drug taken. Among Attenders, 63.3 per cent (38/60) of participants took CBZ and 31.7 per cent (19/60) took PB.

Only monotherapy was applied.

This item showed a highly significant difference in Fisher's exact test with p = 0.0

Table 21: Type of current anti-epileptic medication*

	Non-Attender	Attender	Total
CBZ	4	38	42
	40.0%	63.3%	60.0%
PB	0	19	19
	0.0%	31.7%	27.1%
Pat. does not know	6	3	9
	60.0%	5.0%	12.9%
Total	10	60	70
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	17.2	0.000
N of valid cases	70	

*This item was applicable to 70 participants who took AEDs reliably.

3.8 Intensity of side effects on current antiepileptic treatment

Sixty Attenders and 10 Non-Attenders only were taking AED at the time of the interview. Attenders received their medication from HLH and Non-Attenders from a dispensary.

Thirty per cent (3/10) of Non-Attenders reported no side effects, while 20 per cent (2/10) reported mild side effects

Mild side effects were reported by 5.0 per cent (3/60) of Attenders, reported, 21.7 per cent (13/60) reported moderate side effects and 10 per cent (6/60) participants reported severe side effects. However, the majority of Attenders, 50 per cent (30/60) of participants, reported having no side effects.

The side effects described were: tiredness, dizziness, and orthostatic problems states of disorientation and headache of varying intensiveness.

The difference in the intensity of side effects was identified as significant in Fisher's exact test ($p = 0.013$).

Table 22: Intensity of side effects*

	Non-Attender	Attender	Total
None	3	30	33
	30.0%	50.0%	47.1%
Mild	2	3	5
	20.0%	5.0%	7.1%
Moderate	0	13	13
	0%	21.7%	18.6%
Severe	0	6	6
	0%	10.0%	8.6%
Not answered	5	8	13
	50.0%	13.3%	18.6%
Total	10	60	70
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	10.6	0.013
N of valid cases	70	

*This item was applicable to 70 participants who took AED reliably

3.9 Type of previous anti-epileptic medication

Thirty-eight Non-Attenders remembered the last AED they received from HLH.
50 per cent (19/38) had taken CBZ and 50 per cent (19/40) had taken PB.

Table 23: Type of previous medication*

	Non-Attender
CBZ	19
	33.9%
PB	19
	33.9%
Not answered	18
	32.1%
Total	56
	100.0%

*In total there were 56 Non-Attenders.

3.10 Intensity of side effects with the most recent anti-epileptic drug

Non-Attenders were asked to comment on the side effects of the most recent AED they had received from HLH. The two major groups were made up of 33.9 per cent (19/56) of participants who could not remember and 30.4 per cent (17/56) of participants who had named no side effects.
Mild and moderate side effects were complained of by 12.5 per cent (7/56) of Non-Attenders, whereas 23 per cent (13/56) recalled having suffered severe side effects from their previous drug.

Table 24: Side effects on last drug*

	Non-Attender
None	17
	30.4%
Mild	3
	5.4%
Moderate	4
	7.1%
Severe	13
	23.2%
Not answered	19
	33.9%
Total	56
	100.0%

*In total there were 56 Non-Attenders

4 CONSUMPTION OF ALCOHOL

Non-Attenders began consuming alcohol at a younger age, however their current drinking habits differed only marginally from those of Attenders.
Questions concerning alcohol consumption were posed to participants older than 11 years only.

4.1 Drinking habits

The question after consuming of alcohol was not posed to twelve participants below the age of twelve.
Overall 78.2 per cent (86/110) of the participants answered that they did not drink any form of alcohol and that they never had. The percentages were almost identical with Attenders and Non-Attenders.
Two per cent (1/51) of Non-Attenders and 10.2 per cent (6/58) of Attenders said, they had once consumed alcohol, but had since ceased. 5.9 per cent (3/51) of Non-Attenders and 6.8 per cent (4/58) of Attenders stated that they drank occasionally, which meant not more than twice monthly. Drinking at least once per week was considered as drinking "regularly". This was confirmed by 7.8 per cent (4/51) of Non-Attenders and 3.4 per cent (2/58) of Attenders. 5.9 per cent (3/51) of Non-Attenders and 1.7 per cent (1/58) of Attenders admitted to consuming alcohol on a daily basis. Two of the Non-Attenders were even obviously drunk during the interview.
All in all, the tendency seemed to be that more Attenders had ceased drinking, while more Non-Attenders drank regularly even on a daily basis. However, the Fisher's exact test showed this difference to be not significant ($p = 0.276$).

Table 25: Drinking habits*

	Non-Attender	Attender	Total
No	40	46	86
	78.4%	78.0%	78.2%
Stopped	1	6	7
	2.0%	10.2%	6.4%
Sporadically	3	4	7
	5.9%	6.8%	6.4%
Regularly	4	2	6
	7.8%	3.4%	5.5%
Daily	3	1	4
	5.9%	1.7%	3.6%
Total	51	58	110
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	5.06	0.276
N of valid cases	110	

*The question was not posed to twelve participants below the age of twelve.

4.2 Age when starting drinking alcohol

The age at which they began drinking alcohol was answered by 21 patients. Three patients could not remember the age.

The average age for Non-Attenders was 16.3 (SD: 2.7; median: 16; range: 12-21) years, and 20.5 (SD: 4.7; median: 19; range: 15-30) years for Attenders. The mean age at which Non-Attenders began drinking alcohol was almost four years younger than Attenders. The Mann-Whitney U test showed this as being a significant difference between both groups ($p = 0.023$).

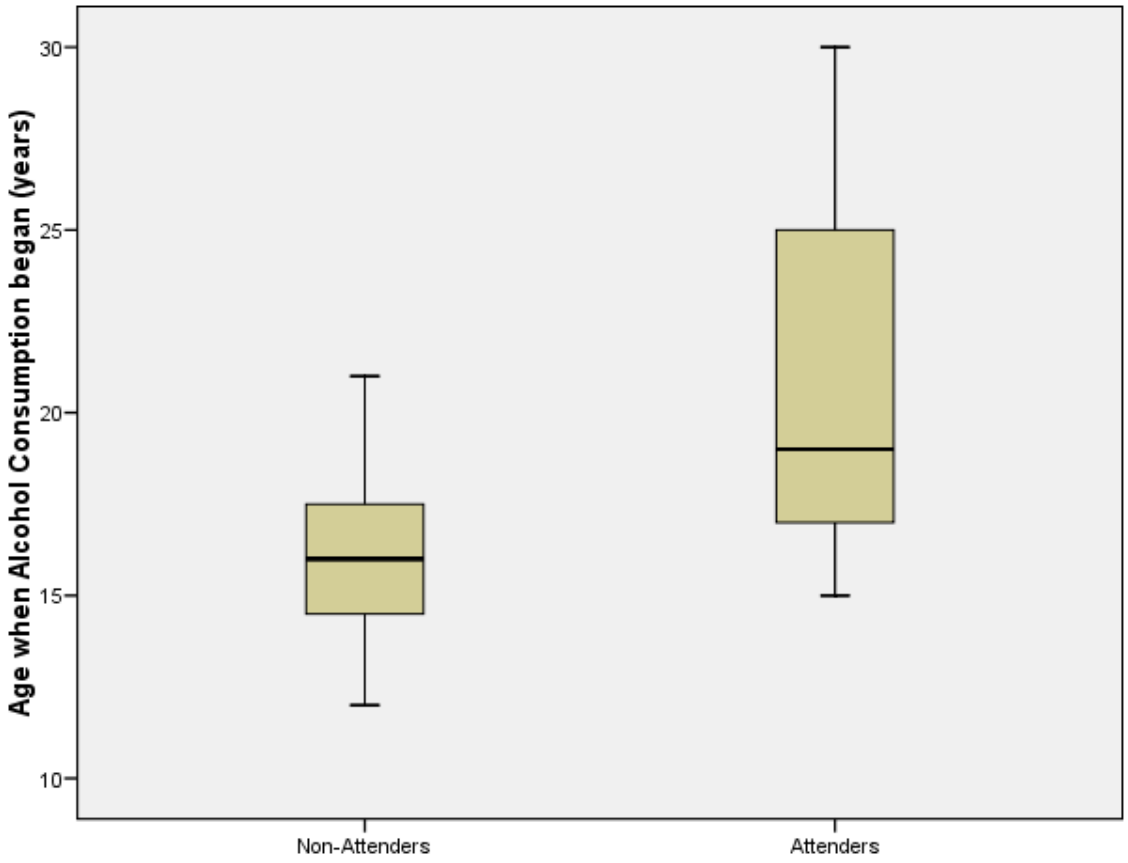

Figure 9: Age when alcohol consumption began

Table 26: Age when alcohol consumption began (yrs.)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	16.3	2.69	16.0	12	21	11
Attender	20.5	4.70	19.0	15	30	10
Total	18.3	4.27	17.0	12	30	21

Mann-Whitney U	23.0
Asymp. Sig. (2-tailed)	0.023

*This item was not applicable to 98 participants because of age or non-consumption; three afflicted participants could not remember their age when started drinking

5 RESULTS OF NEUROLOGICAL AND PSYCHIATRIC EXAMINATION

All interviewed participants were requested to be examined regarding neurological and psychiatric abnormalities. Non-Attenders showed no increased neurological or psychiatric abnormalities over Attenders.

5.1 Neurological examination

Neurological examination involved testing of cranial nerves, motor skills, tone and reflexes as well as sensation. There was no marked difference between Non-Attenders and Attenders in these areas.

There were no problems found in any area of the neurological examination in 62.3 per cent (76/122) of the participants. Of these 66.1 per cent (37/56) were Non-Attenders, and 59.1 per cent (39/66) were Attenders.

26.8 per cent (15/56) of Non-Attenders and 27.3 per cent (18/66) of Attenders were shown to have problems in one to three areas of the examination. The greatest deficits were, by far, motor disorders.

1.8 per cent (1/56) of Non-Attenders and 1.5 per cent (1/66) of Attenders failed in more than three areas of the neurological examination.

The neurological status of 5.4 per cent (3/56) of Non-Attenders and 12.1 per cent (8/66) of Attenders remained uncertain, because no sufficient examination was performed.

No statistically significant difference was found in Fisher's exact test ($p = 0.639$).

Table 27: Neurological examination

	Non-Attender	Attender	Total
Normal	37 66.1%	39 59.1%	76 62.3%
Problems in 1-3 areas	15 26.8%	18 27.3%	33 27.0%
Problems in more than 3 areas	1 1.8%	1 1.5%	2 1.6%
No sufficient data available	3 5.4%	8 12.1%	11 9.0%
Total	56 100.0%	66 100.0%	122 100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	1.97	0.639
N of valid cases	122	

5.2 Psychiatric examination

The mental state evaluation consisted of judging appearance, general behaviour, mood and affect, thought processes, and cognition.

55.7 per cent (68/122) of the participants had a normal mental state. 39.3 per cent (48) of the participants showed psychiatric disorders. Slight or medium depression was by far the most frequent disorder followed by challenging behaviour (esp. in children) and low results on cognitive testing. The psychiatric assessment was unclear in 4.9 per cent (6/122) of the participants.

There was no remarkable difference between Non-Attenders and Attenders. By Fisher's exact testing no significant difference was identified (p = 0.865)

Table 28: Psychiatric examination

	Non-Attender	Attender	Total
Normal, no problem	32	36	68
	57.1%	54.5%	55.7%
Psychiatric problems	22	26	48
	39.3%	39.4%	39.3%
No sufficient data available	2	4	6
	3.6%	6.1%	4.9%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	0.430	0.865
N of valid cases	122	

6 SOCIAL ASPECTS

No significant difference was found concerning the age at marriage nor the age of the spouse nor the number of cohabitants.
Remarkably, almost half of the Non-Attenders (and one quarter of Attenders) chose not to answer the question concerning marital problems.
More Non-Attenders than Attenders reported having been insulted by others because of their disease. Slightly more Attenders affirmed that they had been abused or mistreated.

6.1 Age at first marriage and age of spouse

Of the 122 participants 58 were married, two divorced and one separated at the time of the survey. Five participants couldn't remember at what age they had married.
There was no difference in the mean age at marriage, which in Non-Attenders was 21.9 (SD: 3.5; median: 22.5; range: 15-28) years and 21.8 (SD: 3.5; median: 21.0; range: 15-30) years in Attenders. Thus, also in statistical testing (Mann-Whitney U test) there was no significant difference found (p = 0.756)
Also, the age of male spouses was surprisingly similar: 38.9 (SD: 14.9; median: 35.0; Min: 20; Max: 75) years in Non-Attenders and 38.7 (SD: 14.6; median: 40.0; Min: 19; Max: 72) years in Attenders.

Table 29: Age when married (yrs.)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	21.9	3.54	22.5	15	28	26
Attender	21.8	3.48	21.0	15	30	30
Total	21.8	3.47	22.0	15	30	56

Mann-Whitney U	1619
Asymp. Sig. (2-tailed)	0.756

*The question applied to altogether 61 individuals (who were married at the time of the interview or had been married before) but it was not answered to by five of them.

Table 30: Age of spouse (yrs.)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	38.9	14.9	35.0	20	75	24
Attender	38.7	14.6	40.0	19	72	25
Total	38.8	14.6	35.0	19	75	49

Mann-Whitney U	300
Asymp. Sig. (2-tailed)	0.992

* The question applied to altogether 61 individuals (who were married at the time of the interview or had been married before), but the question was not answered to by 12 of them.

However, there was a noticeable difference when comparing the mean differences of age between participants and their spouses: The mean difference in age (to their spouses) was 9.49 years in female (married or once-married) in Attenders, while it was clearly more in female Non-Attenders, namely 15.5 years.

6.2 Polygamous relationships

Polygamy is legal in Tanzania, (see chapter Methods; II.2; page 24) and is especially prevalent in rural areas.

This question was applied only to those participants who were or had been married. There were 46/61 married participants of the group who were willing to answer this question.

At the time the study was conducted 27.6 per cent (8/29) Non-Attenders and 26.9 per cent 32 (7/32) Attenders stated that they were involved in a polygamous relationship.

This was proportionally more for Non-Attenders than Attenders however these numbers did not yield a significant result in Fisher's exact test (p = 0.533)

Of 15 polygamous living participants there were six males and nine females.

Table 31: Polygamy*

	Non-Attender	Attender	Total
No	12	18	30
	41.4%	56.3%	49.2%
Yes	8	7	15
	27.6%	21.9%	24.6%
Not answered	9	7	16
	31.0%	21.9%	26.2%
Total	29	32	61
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	1.40	0.533
N of valid cases	61	

*The question applied to altogether 61 individuals (who were married at the time of the interview or had been married before).

6.3 Marital problems

13.8 per cent (4/29) of Non-Attenders and 31.3 per cent (10/32) of Attenders indicated that they had marital problems such as inveterate conflicts, frequent quarrels, adultery, and jealousy. One woman reported being the victim of physical abuse.
37.9 per cent (11/29) of Non- Attenders and 43.8 per cent (14/32) of Attenders stated that there were no explicit relationship problems. Remarkably, almost half of the Non-Attenders 48.3 per cent (14/29) chose not to answer this question. In the group of Attenders 25 per cent (8/32) chose not to answer. This tendentious difference was not found significant in the Fisher's exact test with p = 0.127.

Table 32: Marital problems

	Non-Attender	Attender	Total
No	11	14	25
	37.9%	43.8%	41.0%
Yes	4	10	14
	13.8%	31.3%	23.0%
Not answered	14	8	22
	48.3%	25.0%	36.1%
Total	29	32	61
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	4.32	0.127
N of valid cases	61	

*The question applied to altogether 61 individuals (who were married at the time of the interview or had been married before).

6.4 Reasons for being/remaining single

This item was applicable to 61 unmarried participants plus two who were divorced.
The reasons for living as a single person were mostly given by a younger age group: sixty-nine per cent (20/29) of Non-Attenders and 52.9 per cent (18/34) of Attenders were under age of 18. The diagnosis of 'epilepsy' was a hindrance to marriage for 17.2 per cent (5/29) of Non-Attenders and 29.4 per cent (10/34) of Attenders. 3.4 per cent (1/29) of Non-Attenders and 5.9 per cent (2/34) of Attenders gave personal reasons as their answer. For 6.9 per cent (2/29) of Non-Attenders a previous divorce was a hindrance for remarriage.

No answer was given by 3.4 per cent (1/29) of Non-Attenders and 11.8 per cent (4/34) of Attenders.

There was no significant difference observed (p = 0.271).

Table 33: Reason not to marry*

	Non-Attender	Attender	Total
Under age of 18	20	18	38
	69.0%	52.9%	60.3%
Epilepsy	5	10	15
	17.2%	29.4%	23.8%
Personal	1	2	3
	3.4%	5.9%	4.8%
Divorced	2	0	2
	6.9%	0.0%	3.2%
Not answered	1	4	5
	3.4%	11.8%	7.9%
Total	29	34	63
	100.0%	100.0%	100,0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	5.05	0.271
N of valid cases	63	

*item applicable to 61 unmarried participants plus two who were divorced.

6.5 Cohabitants

The number of cohabitants, mostly within the participant's family environment, was almost equal in Non-Attenders and Attenders. There was an average of 7.14 (SD: 3.46; median: 7.00; range: 1-19) people living together with the family of the participant. There was no significant difference (p = 0.762). Thirteen participants didn't answer the question.

Table 34: Cohabitants*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	7.10	3.47	6.50	1	19	50
Attender	7.17	3.47	7.00	1	17	59
Total	7.14	3.46	7.00	1	19	109

Mann-Whitney U	1426
Asymp. Sig. (2-tailed)	0.762

*13 participants did not answer the question.

6.6 Family cohabitation

The question posed here was if participants live in one household with the rest of their family, and, more specifically, whether or not they participated in joint family meals.

Most of the participants (around 90 per cent in both groups) stayed with their nuclear family.

12.5 per cent (7/56) of Non-Attenders and 7.6 per cent (5/66) of Attenders did not live with their families because of a greater need for assistance with their daily tasks. None of them was housed in a specialised facility (such as for the handicapped), instead they were brought to relatives or friends who looked after them.

With 13.8 per cent (8/56) of Non-Attenders' and nine per cent (6/66) of Attenders' families it was not usual for the participant to eat joint meals with family members, because he or she, being handicapped or physically stigmatised, needed constant assistance with eating.

The question was not answered by 1.8 per cent (1/122) of Non-Attenders (in both items).

The differences were not significant by Fisher's exact test (living together: $p = 0.292$; eating together: $p = 0.464$).

Table 35: Patient lives at family's place

	Non-Attender	Attender	Total
No	7	5	12
	12.5%	7.6%	9.8%
Yes	48	61	109
	85.7%	92.4%	89.3%
Not answered	1	0	1
	1.8%	0.0%	0.8%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.03	0.292
N of valid cases	122	

Table 36: Patient joins meals with family

	Non-Attender	Attender	Total
No	7	6	13
	12.5%	9.1%	10.7%
Yes	48	60	108
	85.7%	90.9%	88.5%
Not answered	1	0	1
	1.8%	0.0%	0.8%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	1.57	0.464
N of valid cases	122	

6.7 Economic independence

26 Children of younger age than 16 for this item were excluded from the study. One Attender did not answer the question.

There is no eminent (and no statistical significant: p = 0.821) difference between 44.2 per cent (19/43) of Non-Attenders and 37.7 per cent (20/53) of Attenders, who relied on someone else for their financial or other economic resources. No statistical significance was found (p = 0.821)

Table 37: Economic independence*

	Non-Attender	Attender	Total
No	19	20	39
	44.2%	37.7%	40.6%
Yes	24	32	56
	55.8%	60.4%	45.9%
Not answered	0	1	1
	0.0%	1.9%	1.0%
Total	43	53	96
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	1.09	0.821
N of valid cases	96	

*This item applied to 96 participants aged 16 years or older

6.8 Physical independence

One child younger than six years was excluded, because an entire physical independence is assumed to be possible only from this age on. One Attender did not answer the question. Of the remaining 121 participants, seven were physically dependant on others. Of those 8.9 per cent (5/56), were Non-Attenders. This was more than the 3.1 per cent (2/65) Attenders who were dependant. The difference had no statistical significance for this item (p = 0.247).

Table 38: Physical independence*

	Non-Attender	Attender	Total
No	5	2	7
	8.9%	3.1%	5.8%
Yes	51	62	113
	91.1%	95.4%	93.4%
Not answered	0	1	1
	0.0%	1.5%	0.8%
Total	56	65	121
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.58	0.247
N of valid cases	121	

*This item was not applicable to one child under the age of six

6.9 The main care-giver

This question dealt with which person close to the patient felt mainly responsible for his/ her well-being. One Non-Attender did not answer this question.

With Non-Attenders the participants predominantly cared for themselves. This was followed quite closely by parents, being the main providers of care. Only minimal contributions were made by spouses, children or others.

With Attenders self-care was also the prevalent mode of support. Compared with Non-Attenders the gap was somewhat wider where parents were listed as the main care-givers. Similar to Non-Attenders, only minimal care was received from other groups.

There was no statistical significance found in the analysis of this item (p = 0.777).

Table 39: The main care-giver

	Non-Attender	Attender	Total
Patient him/herself	25	37	62
	44.6%	56.1%	50.8%
Parents	23	21	44
	41.1%	31.8%	36.1%
Husband	3	4	7
	5.4%	6.1%	5.7%
Others	3	3	6
	5.4%	4.5%	4.9%
Children	1	1	2
	1.8%	1.5%	1.6%
Not answered	1	0	1
	1.8%	0.0%	0.8%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	3.08	0.777
N of valid cases	122	

6.10 Hours worked on days with and without seizures

This item was applicable for participants more than eight years old, because within the Tanzanian cultural context, children are mostly required to help in household and farming from this age.

In general, there was no apparent discrepancy between Non-Attenders and Attenders in the following schedules.

Hours (h) worked on normal days was 5.46 (SD: 2.93; median: 6.0; range: 0-10) h by Non-Attenders and 5.91 (SD: 2.99; median: 7.0; range: 0- 10) h by Attenders.

Understandably on days when seizures occurred patients worked, on average, less hours. Statistics ranged between zero and eight hours, depending on the severity of the individual disorder. On average Non-Attenders worked 2.32 (SD: 2.42; median: 2.00; range: 0- 7) h and Attenders 2.64 (SD: 2.65; median: 2.00; range: 0-8) h.

In Mann-Whitney U test there was no significant difference in both items (normal days: $p = 0.303$, days with seizures: $p = 0.582$).

Table 40: Hours of work on normal days*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	5.46	2.93	6.00	0	10	50
Attender	5.91	2.99	7.00	0	10	64
Total	5.71	2.96	6.00	0	10	114

Mann-Whitney U	1483
Asymp. Sig. (2-tailed)	0.303

*Question was not applicable to eight participants, who were under the age of eight

Table 41: Hours of work on days with seizures*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	2.32	2.42	2.00	0	7	48
Attender	2.64	2.65	2.00	0	8	61
Total	2.50	2.54	2.00	0	8	109

Mann-Whitney U	1377
Asymp. Sig. (2-tailed)	0.582

*Answer was not given by five participants. Question was not applicable to eight participants, who were under the age of eight.

6.11 Social network

121 patients older than five years were included, because the awareness of friendship is not given with certainty in younger age. One Attender did not answer.

Non-Attenders appeared to be socially less integrated. 21.4 per cent (12/56) of the Non-Attenders indicated that they had no close friends or intimates they could trust and talk with. In the group of Attenders only 12.3 per cent (8/65) said so.

The difference was not significant in Fisher's exact test ($p = 0.222$).

Table 42: Social network*

	Non-Attender	Attender	Total
No	12	8	20
	21.4%	12.3%	16.5%
Yes	44	56	100
	78.6%	86.2%	82.6%
Not answered	0	1	1
	0.0%	1.5%	.8%
Total	56	65	121
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.50	0.222
N of valid cases	121	

* One child under the age of six was excluded.

6.12 Explicitly aggressive behaviour toward participants

Participants were cautiously requested to divulge whether or not they were ever directly insulted, mistreated or even abused as a result of their epilepsy. The main carer was asked to answer in place of a child. Thus, in this item all patients were included, also the youngest one, aged five years. Two Attenders gave no answer concerning both items

All in all the positive answers to this question may have been underrated (see chapter Discussion; V.1; page 123f).

In this sample slightly more Non-Attenders indicated having been insulted, while slightly more Attenders reported being mistreated or abused. In these relatively small numbers there was no significant difference found in the statistical analysis.

Insults

30.4 per cent (17/56) of Non-Attenders, which is proportionally more than the 19.7 per cent (13/66) of Attenders, reported having been insulted by others because of their disease on at least one occasion.

Table 43: Insults

	Non-Attender	Attender	Total
No	39	51	90
	69.6%	77.3%	73.8%
Yes	17	13	30
	30.4%	19.7%	24.6%
Not answered	0	2	2
	0.0%	3.0%	1.6%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.95	0.191
N of valid cases	122	

Abuse/mistreatment

Within this item proportionally more Attenders, namely 16.7 per cent (11/66) reported having been mistreated or abused. 10.7 per cent (6/56) of Non-Attenders reported likewise.

Table 44: Abuse/mistreatment

	Non-Attender	Attender	Total
No	50	53	103
	89.3%	80.3%	84.4%
Yes	6	11	17
	10.7%	16.7%	13.9%
Not answered	0	2	2
	0.0%	3.0%	1.6%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.35	0.347
N of valid cases	122	

7 ATTITUDES TOWARDS AND PERCEPTIONS OF EPILEPSY

In the majority of items Attenders and Non-Attenders showed no considerable differences. Non-Attenders, however, estimated themselves as being more efficient with regard to their work performance than Attenders did. Never the less proportionally more than double the number of Non-Attenders compared to Attenders stated to cope badly with their epilepsy.

The fact was also remarkable that Non-Attenders were more often certain than Attenders that others were not aware of their neurological illness.

7.1 Role in domestic life

This item was applicable for participants older than eight years old, because within the Tanzanian cultural context, children are mostly required to help in household and farming from this age.

Whereas 3.8 per cent (2/52) of the Non-Attenders and 3.2 per cent (2/62) of Attenders described their contribution as being unhelpful, 19.2 per cent (10/52) Non-Attenders and 25.8 per cent (16/62) Attenders described themselves as being of “little help” in assisting with daily tasks.

The predominant portion of both groups saw themselves as being equal with other members of society: The statistics were 76.9 per cent (40/52) of Non-Attenders, and 71.0 per cent (44/62) of Attenders.

The difference was calculated to have no statistical significance ($p = 0.760$).

Table 45: Role in domestic life*

	Non-Attender	Attender	Total
No help	2	2	4
	3.8%	3.2%	3.5%
Little help	10	16	26
	19.2%	25.8%	22.8%
Equal member of social group	40	44	84
	76.9%	71.0%	73.7%
Total	52	62	114
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	0.822	0.760
N of valid cases	114	

*The item was applicable for 114 participants from the age of eight years

7.2 Situation in the community

The main carer responded to the question in place of children younger than 12 years. Both groups answered that on the whole, they estimated their situation in the community to be no better or worse than for people who did not suffer from epilepsy. These were 71.4 per cent (40/56) of Non-Attenders and even more, 78.8 per cent (52/66) of Attenders. However, a sizeable group, 26.8 per cent (15/56) of Non-Attenders, felt as if they were in a worse situation and 21.2 per cent (14/66) of the Attenders agreed that this was also true for them. One Non-Attender (1.8 per cent) stated that she felt her situation to be better than others.

There was no statistical significance found within these minor differences (p = 0.453).

Table 46: Situation in community

	Non-Attender	Attender	Total
Worse	15	14	29
	26.8%	21.2%	23.8%
The same	40	52	92
	71.4%	78.8%	75.4%
Better	1	0	1
	1.8%	0.0%	0.8%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	1.74	0.453
N of valid cases	122	

7.3 Coping with epilepsy

Children under the age of 12 were excluded because it cannot be assumed that they could estimate the real impact of epilepsy to their lives before adolescence. One Attender did not answer the question.

In proportion nearly double the Non-Attenders stated that they coped poorly with their epilepsy compared to Attenders where almost 90 per cent thought they coped moderately or well with the "falling disease". These two groups (moderately and good) combined represent about 80 per cent of the answers of Non-Attenders.

This difference was found to be significant in Fisher's exact test with p = 0.031.

Table 47: Coping with epilepsy*

	Non-Attender	Attender	Total
Bad	11	7	18
	22.0%	11.9%	16.5%
Moderately	10	25	35
	20.0%	42.4%	32.1%
Good	29	26	55
	58.0%	44.1%	50.5%
Not answered	0	1	1
	0.0%	1.7%	0.9%
Total	50	59	109
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	7.72	0.031
N of valid cases	109	

*This item was not applicable to 13 participants younger than 12 years.

7.4 Work performance

This item was applicable for participants more than seven years old, because within the Tanzanian cultural context, children are mostly required to help in household and farming from this age onwards. Eight of 114 participants (7.8 per cent; four Attenders and four Non-Attenders) did not answer this question.

Nearly 70 per cent (37/53) of Non-Attenders estimated that on average their work performance was normal. 5.7 per cent (3/53) of them considered their performance as being even better than others in the community. 15.1 per cent (8/53) of Non-Attenders described their personal performance as being worse.

In comparison, 32.3 per cent (20/62) of Attenders found their work performance to be worse than others in the community, although the majority, 59.7 per cent (37/62), estimated their performance as being similar to that of others. 1.6 per cent (1/62) considered their performance as being even better.

Hence Non-Attenders tended to estimate themselves on the whole as being more effective than Attenders concerning their contribution to the work force.

In Fisher's exact test there was no significance found in this difference (p = 0.127).

Table 48: Work performance*

	Non-Attender	Attender	Total
Worse	8	20	28
	15.1%	32.3%	24.3%
Normal	37	37	74
	69.8%	59.7%	64.3%
Better	3	1	4
	5.7%	1.6%	3.5%
Not answered	4	4	8
	9.4%	6.5%	7.8%
Total	52	62	114
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	5.55	0.127
N of valid cases	114	

This item was applicable to 114 participants older than seven years.

7.5 Awareness of people in the community concerning the patient's affliction with epilepsy

The main carer responded to the question in place of children younger than 12 years. Two Non-Attenders did not answer this question.

The majority of participants in the collective (around 85 per cent) stated that people in the community were aware of their / respectively their children's neurological disease.

12.5 per cent (7/56) of Non-Attenders and 18.6 per cent (12/66) of Attenders specified that they had informed their friends and relatives personally. The greater part of both groups, namely 64.3 per cent (36/56) of Non-Attenders and 75.8 per cent (50/66) of Attenders,

surmised that people had learned of it from some source or had personally seen them during a seizure.

The difference between Non-Attenders and Attenders concerning the assumption that people were not aware they suffered from epilepsy was noticeable. Remarkably, more Non-Attenders, 19.6 per cent (11/56), were sure that others did not know but only 6.1 per cent (4/66) of Attenders were equally sure.

This difference was found statistically significant in Fisher's exact test with p = 0.036.

Table 49: Awareness of others

	Non-Attender	Attender	Total
Pt told them	7	12	19
	12.5%	18.2%	15.6%
They know from somewhere/saw patient having seizure	36	50	86
	64.3%	75.8%	70.5%
They don't know	11	4	15
	19.6%	6.1%	12.3%
Not answered	2	0	2
	3.6%	0.0%	1.6%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	7.58	0.036
N of valid cases	122	

7.6 Participant's sense of debasement and prejudice toward him/her

Children under the age of 12 were excluded, because the awareness and expression of these specific feelings cannot be assumed to be developed before adolescence. Two Attenders did not answer to these three questions.

The following three items outline how participants felt treated by their environment. Around 20 per cent of those interviewed reported regularly sensing that other people treated them differently or unfairly in comparison with others.

Non-Attenders were more inclined to think that other people felt uncomfortable around them and would therefore avoid them, while Attenders more frequently saw themselves being regarded as inferior.

However, there was no statistically significant discrepancy between both groups in these three items.

Other people feeling uncomfortable

From the 109 participants surveyed, 22.0 per cent (11/50) of Non-Attenders and 15.3 per cent (9/59) of Attenders thought that other people felt uncomfortable in their presence.

Table 50: People feel uncomfortable

	Non-Attender	Attender	Total
No	39	48	87
	78.0%	81.4%	79.8%
Yes	11	9	20
	22.0%	15.3%	18.3%
Not answered	0	2	2
	0.0%	3.4%	1.8%
Total	50	59	109
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.00	0.455
N of valid cases	109	

*This item was not applicable to 13 participants younger than 12 years.

Dismissive treatment due to being regarded as inferior

Twenty per cent (10/50) of Non-Attenders and nearly thirty per cent (17/59) of Attenders felt that they were regarded as being inferior by others.

Table 51: Patient feels inferior

	Non-Attender	Attender	Total
No	40	40	80
	80.0%	67.8%	73.4%
Yes	10	17	27
	20.0%	28.8%	24.8%
Not answered	0	2	2
	0%	3.4%	1.8%
Total	50	59	109
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.86	0.193
N of valid cases	109	

*This item was not applicable to 13 participants younger than 12 years.

Avoidance

Twenty per cent (11/50) of Non-Attenders and 16.9 per cent (10/59) of Attenders felt they were avoided by other members of the community.

Table 52: Avoidance

	Non-Attender	Attender	Total
No	39	47	86
	78.0%	79.7%	78.9%
Yes	11	10	21
	22.0%	16.9%	19.3%
Not answered	0	2	2
	0.0%	3.4%	1.8%
Total	50	59	109
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	1.70	0.507
N of valid cases	109	

*This item was not applicable to 13 participants younger than 12 years.

Summarising, it can be said that the majority of Non-Attenders were of the opinion that others might avoid them or feel uncomfortable around them, while the majority of Attenders felt regarded as being inferior.

However, there was no significant difference in these numbers.

7.7 Perceptions of epilepsy

Adult and adolescent participants were asked what, in their opinion, epilepsy most probably originated from. Children up to 16 years of age were excluded, because a scientific perception and differentiation from traditional explanations required a certain maturity. Two participants did not answer this question (one Attender and one Non-Attender)

31.3 per cent (30/96) of those participating had no idea or viable explanation.

26.0 per cent (25/96) of the participants believed it was witchcraft or some kind of curse; this belief was commonly held. The same as “human hand”, according to the concept that a person wanted to harm them. 20.8 per cent (20/96) of those participating were sure that this was the reason.

9.4 per cent (9/96) of the people were able to adequately describe a scientific background for the illness. They had received this information either from medical staff, in school or from books.

2.1 per cent (2/96) of the participants just assumed that the sole cause was hereditary in nature as there were several family members affected; 8.3 per cent (8/96) of those participating had some other idea.

Summarising, slightly more Attenders than Non-Attenders were aware of a scientific explanation for the illness and the figures differed only marginally when it came to traditional explanations such as „human hand” and/or “witchcraft”.

There was no significance found in Fisher’s exact test ($p = 0.626$).

Table 53: Perceptions of epilepsy*

	Non-Attender	Attender	Total
No idea	14	16	30
	32.6%	30.2%	31.3%
Witchcraft	13	12	25
	30.2%	22.6%	26.0%
Human hand	7	13	20
	16.3%	24.5%	20.8%
Inherited	1	1	2
	2.3%	1.9%	2.1%
Scientific background	2	7	9
	4.7%	13.2%	9.4%
Other idea	5	3	8
	11.6%	5.7%	8.3%
Not answered	1	1	2
	2.3%	1.9%	2.1%
Total	43	53	96
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	4.65	0.626
N of valid cases	96	

*This item applied to 96 participants older than 15 years

7.8 Medium that influenced the perception of epilepsy

As in the previous item children up to age 16 were excluded.

Overall 45.8 per cent (44/96) of the participants answered "common belief". This was the most frequent statement.

The perception of 8.3 per cent (8/96) of the participants had been influenced by medical staff.

6.3 per cent (6/96) were influenced by the opinion of other people in community.

Active research by the patients themselves was stated by 3.1 per cent (3/96) of the participants. 8.3 per cent (8/96) of those participating received their perception about epilepsy from other sources.

28.1 per cent (27/96) did not answer to the question (nine Non-Attenders, 18 Attenders).

No significant difference could be observed between Attenders and Non-Attenders ($p = 0.530$).

Table 54: Medium that influenced the perception*

	Non-Attender	Attender	Total
Common belief	22	22	44
	51.2%	41.5%	45.8%
Medical staff	2	6	8
	4.7%	11.3%	8.3%
People in community	4	2	6
	9.3%	3.8%	6.3%
Active research	2	1	3
	4.7%	1.9%	3.1%
Other	4	4	8
	7.1%	6.1%	6.6%
Not answered/patient could not decide	9	18	27
	20.9%	34.0%	28.1%
Total	43	53	96
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	5.02	0.431
N of valid cases	96	

*This item applied to 96 participants older than 15 years

8 TRADITIONAL TREATMENT

According to the below results, Non-Attenders were no more inclined to visit traditional healers than Attenders.

8.1 Use of herbal medicine and its effect on seizure frequency

There seems to be a wide variety of herbal medicine that is used for different kinds of applications. Parts of the plants should be consumed as a powder or tea or processed to a paste or infusion for unction.

The question was if herbal treatment had ever been used. Of 122 patients, two did not answer this question; 39.3 per cent (48/122) confirmed having used herbal medication. 30.4 per cent (17) of Non-Attender compared to 47 per cent (31) of Attenders, confirmed this.

Of the participants who had indicated having tried herbal treatment, two Non-Attenders and one Attender did not respond to the question as to whether or not there had been an effect on the frequency of seizures.

2.2 per cent (1/45) of the participants (Non-Attender) was sure that herbal treatment had reduced the seizures. The remaining 9.8 per cent (44/45) stated not having experienced any lasting relief from seizures using herbal treatment.

There was no significant difference between Non-Attenders and Attenders; p-value was 0.11.

Table 55: Herbal treatment

	Non-Attender	Attender	Total
No	38	34	72
	67.9%	51.5%	59.0%
Yes	17	31	48
	30.4%	47.0%	39.3%
Not answered	1	1	2
	1.8%	1.5%	1.6%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	3.73	0.113
N of valid cases	122	

Table 56: Reduction of seizure frequency by herbal treatment*

	Non-Attender	Attender	Total
No	14	30	44
	93.3%	100.0%	97.8%
Yes	1	0	1
	6.7%	0.0%	2.2%
Total	15	30	45
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.54	0.333
N of valid cases	45	

*The question applied to 48 patients who took herbal treatment; data of three of them was not given.

8.2 Application of scarification and its effect on the frequency of seizures

Of 122 Participants 21.3 per cent (26/122) had one or more scars. 75.4 per cent (92) had no specific scarification from epilepsy. The statistics did not differ much between Non-Attenders and Attenders.

61.5 per cent (16/26) of the participants reported having no relief from this kind of treatment. 15.4 per cent (4/26) participants noticed amelioration. 23.1 per cent (6/26) were uncertain and abstained from answering.

In both items no significant difference between Non-Attenders and Attenders was noted with $p = 0.90$ in the Fisher's exact test.

Table 57: Scarifications

	Non-Attender	Attender	Total
No	43	49	92
	76.8%	74.2%	75.4%
Single	3	4	7
	5.4%	6.1%	5.7%
Multiple	9	10	19
	16.1%	15.2%	15.6%
Not answered	1	3	4
	1.8%	4.5%	3.3%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	0.80	0.902
N of valid cases	122	

Table 58: Reduction of seizure frequency by scarification*

	Non-Attender	Attender	Total
No	7	9	16
	58.3%	64.3%	61.5%
Yes	3	1	4
	25.0%	7.1%	15.4%
Not answered	2	4	6
	16.7%	28.6%	23.1%
Total	12	14	26
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	1.70	0.557
N of valid cases	26	

*The question applied to 26 patients who received scarifications.

9 ADHERENCE TO HAYDOM LUTHERAN HOSPITAL CONCERNING EPILEPSY TREATMENT AND GENERAL USE OF HEALTH SERVICES

The most prevalent reason for Non-Attenders not returning to the clinic was that either the seizures had ceased or they were not satisfied with treatment, whereas Attenders missed the occasional appointment because of a lack of time. Difficult travelling conditions to the hospital were given as a reason by both Non-Attenders and Attenders for not attending. Some Non-Attenders did not return because they were told by the nurses from the epilepsy clinic not to come back.
A significant difference showed up within the item “use of healthcare”, which was on average better with Attenders than with Non-Attenders.

9.1 Regular attendance

The regularity of attendance was graded as follows: never missed an appointment, missed appointments seldom (2 times per year or less), missed appointments sometimes (more than half of appointments were kept) missed appointment often (less than half the appointments were kept) or have not come to Haydom Lutheran Epilepsy Clinic for full 12 months, which qualified them as Non-Attenders to HLH.

Almost 90 per cent of Attenders had never or very seldom missed an appointment (Never missed: 69.7 per cent (46/66) and seldom missed: 21.2 per cent (14/66).
Less than half of the appointments were missed by 6.1 per cent (4/66) of the Attenders and more than half of the appointments per year were missed by 1.5 per cent (1/66) of the Attenders. However, these participants had been to HLH within the year before, that is why they were grouped as Attenders (see chapter Methods; II.3.2; page 28).
As an exception, one Attender, 1.5 per cent (1/66), stated that she had not been to hospital for more than one year because she was a relative of a nurse working at the Haydom Lutheran Epilepsy Clinic. This special situation resulted in her being frequently monitored, and for this reason she was considered to be an “Attender”.
The statistics for Non-Attenders was just the opposite with 89.3 per cent (50/56) not having participated in a clinical follow-up for more than 12 months. 3.6 per cent (2/56) of the Non-Attenders had only occasionally missed an appointment while another 3.6 per cent (2/56) had missed less than half. 1.5 per cent (1/56) had missed more than half of the appointments. Those were patients with benign courses of epilepsy, who were given follow-up invitations in less frequent intervals, what could result in the situation that they

had not been to Haydom for more than one year even when they only missed appointments occasionally. For further explanation of sampling see chapter Methods (II.3.2; page 28).

One Non-Attender refused to reply to the question.

Table 59: Regular attendance

	Non-Attender	Attender	Total
Never missed	0 0%	46 69.7%	46 37.7%
Very seldom missed (< 2/year)	2** 3.6%	14 21.2%	16 13.1%
Sometimes missed (less than half of appointments)	2** 3.6%	4 6.1%	6 4.9%
Often missed (more than half of appointments)	1 1.8%	1*** 1.5%	2 1.6%
Never there this year	50 89.3%	1* 1.5%	51 41.8%
Not answered	1 1.8%	0 0.0%	1 0.8%
Total	56 100.0%	66 100.0%	122 100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	128	0.000
N of valid cases	122	

*This patient was a relative of a nurse

**Interval since last attendance > 1 year

***Interval since last Attendance < 1 year

9.2 Reasons for the last visit at Haydom Lutheran Hospital

This item deals with the reason for the participants' last visit to HLH.

39.9 per cent (19/56) of Non-Attenders gave keeping an appointment as an important reason for their last visit. This reason was also given by 51.5 per cent (34/66) of the Attenders. Another frequent reason was: "for picking up drugs": 14.3 per cent (8/56) of Non-Attenders and 27.3 per cent (18/66) of the Attenders gave this reason.

The occurrence of one or more (partly severe) seizures was the reason given by 1.8 per cent (1/56) of Non-Attenders and 9.1 per cent (6/66) of Attenders for their last visit.

6.1 per cent (4/66) of the Attenders came to HLH as the result of an invitation sent out to PWE by a field co-worker offering an EEG examination.

1.8 per cent (1/56) of Non-Attenders and 1.5 per cent (1/66) of the Attenders came to HLH for the treatment of some other disease. 1.5 per cent (1/66) of the Attenders was visiting a relative, who was an inpatient, and used this as an opportunity to visit the Epilepsy Clinic (labelled “other reasons”).

48.2 per cent (27/56) of the Non-Attenders were unable to give a specific reason along with three per cent (2/66) of the Attenders.

Summarising, more Attenders than Non-Attenders came for a scheduled appointment. More Attenders came after a (perhaps unusually severe) seizure and in order to pick up some AED.

Only those who were “Attenders”, travelled to Haydom, as a result of the invitation to be examined by the (newly-installed) EEG.

The majority of Non-Attenders could not recall the reason for their last visit.

The difference in these answers was highly significant (Fisher’s exact test; $p < 0.001$).

Table 60: Reason for last visit

	Non-Attender	Attender	Total
Appointment	19 33.9%	34 51.5%	53 43.4%
Seizure	1 1.8%	6 9.1%	7 5.7%
Other disease	1 1.8%	1 1.5%	2 1.6%
Drugs	8 14.3%	18 27.3%	26 21.3%
Other reason	0 0.0%	1 1.5%	1 0.8%
Invitation for EEG	0 0.0%	4 6.1%	4 3.3%
Not answered/Patient could not remember	27 48.2%	2 3.0%	29 23.8%
Total	56 100.0%	66 100.0%	122 100.0%

	Value	Exact Sig. (2-sided)
Fisher’s exact test	39.9	0.000
N of valid cases	122	

9.3 Reasons for not attending the Haydom Lutheran Epilepsy Clinic for appointments

This item was answered by 74 participants, 56/56 Non-Attenders and 18/65 Attenders, who missed appointments occasionally. The latter reported which factor had mostly detained them from regularly attending the Haydom Lutheran Epilepsy Clinic.

There were several reasons, why patients did not come (regularly) to the hospital. The most prominent, for 35.6 per cent (23/74) of the participants, being that the seizures had ceased and they thought they needed no more treatment. Secondly, 17.6 per cent (13/74) of the participants refrained because of the adverse travelling conditions. 14.3 per cent (11/74) could not find the time to come to HLH because of their busy schedule. 13.5 per cent (10/74) were dissatisfied with the treatment (as previously mentioned: side effects, no response to treatment or other personal reasons). Only participants from the “Non-Attender” group were dissatisfied.

10.8 per cent (8/74) of the “Non-Attenders” received treatment from the dispensary.

The cause which prevented 2.7 per cent (2/74) of the Attenders from attending were of a domestic nature (problems at home). 2.7 per cent (2/74) of “Non-Attenders” were told to stop attending for follow-up treatment by a staff member of the epilepsy clinic.

The differences between the groups were as follows: For “Non-Attenders” the major cause was a lack of time, whereas adverse travelling conditions and problems at home (domestic) were the predominant reasons for not keeping an appointment for “Attenders”.

Further important reasons for failing to keep appointments for “Non-Attenders”, were, that seizures had ceased or become less frequent, they were receiving treatment elsewhere or a lack of satisfaction with the treatment at HLH.

The differences, as tested by the Fisher’s exact test, were highly significant ($p < 0.001$)

Table 61: Reason for non-attendance*

	Non-Attender	Attender	Total
No time	4	7	11
	7.1%	38.9%	14.9%
No seizures	21	2	23
	37.5%	11.1%	31.1%
Rough journey	7	6	13
	12.5%	33.3%	17.6%
Treatment somewhere else	8	0	8
	14.3%	.0%	10.8%
Not satisfied with treatment	10	0	10
	17.9%	.0%	13.5%
Problems at home	0	2	2
	0.0%	11.1%	2.7%
Other reason	4	1	5
	7.1%	5.6%	6.8%
Was told to stop follow-up	2	0	2
	3.6%	0.0%	2.7%
Total	56	18	74
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	24.7	0.000
N of valid cases	74	

*This item applied to 74 participants, who reported (partial) non-attendance

9.4 Dispensing of anti-epileptic drugs from a dispensary

The majority, 61.5 per cent (75/122) of the participants, equally distributed between "Non-Attenders" and "Attenders", lacked sufficient information regarding the dispensing of anti-epileptic drugs from a nearby dispensary.

19.6 per cent (11/56) of "Non-Attenders" and 12.1 per cent (8/66) of "Attenders" were aware that AED was dispensed at competent county dispensaries.

On the other hand, 25 per cent (14/56) of "Non-Attenders" and 21.2 per cent (14/66) of "Attenders" were ignorant of the fact.

These differences were not significant ($p = 0.378$).

Table 62: Distribution of drugs in dispensary

	Non-Attender	Attender	Total
No	14	14	28
	25.0%	21.2%	23.0%
Yes	11	8	19
	19.6%	12.1%	15.6%
Patient had no information, if AED were distributed at the dispensary	31	44	75
	55.4%	66.7%	61.5%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	1.93	0.378
N of valid cases	122	

9.5 Anti-epileptic drugs from a dispensary

6.6 per cent (8/122) of the participants regularly received drugs from a dispensary. These were all Non-Attenders (14.3 per cent (8/56)). One Non-Attenders did not answer the question.

Those differences were highly significant (p = 0.001).

Table 63: Anti-epileptic drugs from dispensary

	Non-Attender	Attender	Total
No	47	66	113
	83.9%	100.0%	92.6%
Yes	8	0	8
	14.3%	0.0%	6.6%
Not answered	1	0	1
	1.8%	0.0%	0.8%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	11.9	0.001
N of valid cases	122	

9.6 Instructions by hospital staff to discontinue treatment

11.9 per cent (7/56) of Non-Attenders and three per cent (2/69) of Attenders had been told, at some point, by nurses at the hospital not to return as they (the nurses) estimated that the disease no longer required treatment. This occurred in six cases. Two of the cases involved women who were planning to become pregnant and one further case was due to extreme side effects.

The difference was nearly significant in the Fisher's exact test (p = 0.079).

Table 64: Instructed by hospital staff to discontinue treatment

	Non-Attender	Attender	Total
No	49	64	113
	87.5%	97.0%	92.6%
Yes	7	2	9
	12.5%	3.0%	7.4%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	8.74	0.079
N of valid cases	122	

9.7 Healthcare service use

Participants under the age of 16 were excluded from this item, because the adolescents were only from that age on in a position to decide on their own when to use the health care service. 8.3 per cent (8/96) of the participants gave no answer (one Non-Attender and seven Attenders)

The use of healthcare services was, on average, better with Attenders than Non-Attenders.

7.0 per cent (3/43) of Non-Attenders stated that they were not intending to use public healthcare services. 30.2 per cent (13/43) of the Non-Attenders said that they would only seek healthcare help when they were critically ill, but did not intended to use it for birthing assistance. This opinion was also shared by 20.8 per cent (11/53) of the Attenders.

The largest contingent was made up of 46.5 per cent (20/43) of Non-Attenders and 54.7 per cent (29/53) of Attenders, who said that they would come to hospital, when they fell very ill, and the women – whenever possible - also for birthing assistance.

14.0 per cent (6/43) of Non-Attenders and 11.3 per cent (6/53) of Attenders said that they would go to the hospital every time they felt so sick that they could not perform their daily tasks.

The Fisher's exact test ($p = 0.080$) indicates there was nearly a significant difference between the groups.

Table 65: Healthcare use*

	Non-Attender	Attender	Total
Never	3	0	3
	7.0%	.0%	3.1%
When urgently ill. not for birth	13	11	24
	30.2%	20.8%	25.0%
When very ill and / or for birth	20	29	49
	46.5%	54.7%	51.0%
Always when ill	6	6	12
	14.0%	11.3%	12.5%
Not answered	1	7	8
	2.3%	13.2%	8.3%
Total	43	53	96
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	7.88	0.080
N of valid cases	96	

*This item applied to 96 participants, older than 15 years.

10 EDUCATION

Attenders frequented school on a more regular basis than Non-Attenders who mostly gave socio-economic reasons for their lack of attendance. In all items concerning school education only participants from age of six and older were included.

10.1 School attendance

This item applied to 121 participants from six years on.

67.8 per cent (82/121) of the participants stated that they had attended school or were attending school at the time of the interview. Among Non-Attenders 71.4 per cent (40/56) had received a school education. 64.6 per cent (42/65) of Attenders had likewise received a school education.

The study revealed a discrepancy in school attendance between Attenders and Non-Attenders. The Pearson Chi-Square test showed no significance in this discrepancy (p = 0.443).

Table 66: Attendance at school*

	Non-Attender	Attender	Total
No	16	23	39
	28.6%	35.4%	32.2%
Yes	40	42	82
	71.4%	64.6%	67,8%
Total	56	65	121
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Pearson Chi-Square	0.64	0.443
N of valid cases	121	

*This item applied to 121 participants, older than five years.

10.2 Level of education

This item was valid for 82 participants who had received school education.

53.7 per cent (44/82) of the participants had attended, or were presently attending, Primary School. 34.1 per cent (28/82) had dropped out of Primary School.

Secondary School was or had been attended by 6.1 per cent (5/82); one of 82 (1.2 per cent), a Non-Attender had dropped out.

2.4 per cent (2/82) of the participants only had attended a Chekachea (a more traditional facility where young children are looked after). They had had no other schooling. Both were Attenders.

The question was not answered to by 2.4 per cent (2/82) of the valid participants.

There was no significant difference between Attenders and Non-Attenders in the Fisher's exact test (p = 0.440)

Table 67: Level of education*

	Non-Attender	Attender	Total
Chekachea	0	2	2
	0.0%	4.8%	2.4%
Dropped out of primary school	14	14	28
	35.0%	33.3%	34.1%
Primary school	20	24	44
	50.0%	57.1%	53.7%
Dropped out of secondary school	1	0	1
	2.5%	0.0%	1.2%
Secondary school	3	2	5
	7.5%	4.8%	6.1%
Not answered	2	0	2
	5.0%	0.0%	2.4%
Total	40	42	82
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	4.80	0.440
N of valid cases	82	

* Item was valid for 82 participants who had received school education.

10.3 Regularity of school attendance

This item applied to 121 participants, older than five years.

A regular school attendance was confirmed by 35.7 per cent (20/56) of Non-Attenders and 46.2 per cent (30/65) of Attenders. 32.1 per cent (18/56) of Non-Attenders and 18.5 per cent (12/65) of Attenders had attended school sporadically.

28.6 per cent (16/56) of Non-Attenders and 30.8 per cent (20/65) of Attenders stated that they did not attend school. The question as not answered to by 3.6 per cent (2/56) of Non-Attenders and 4.6 per cent (3/65) of Attenders. In general Attenders tended to frequent school more regularly than Non-Attenders whose attendance was rather sporadic.

However, there was no significant difference in the Fisher's exact test (p = 0.347).

Table 68: Regularity of school attendance*

	Non-Attender	Attender	Total
No attendance	16	20	36
	28.6%	30.8%	29.8%
Sporadic	18	12	30
	32.1%	18.5%	24.8%
Regular	20	30	50
	35.7%	46.2%	41.3%
Not answered	2	3	5
	3.6%	4.6%	4.1%
Total	56	65	121
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	3.23	0.347
N of valid cases	121	

*This item applied to 121 participants older than five years.

10.4 Reasons for staying home from school

The reasons, why participants did not attend school (both "never" and "not regularly") were varied and widespread. Fourteen Non-Attenders and 20 Attenders answered to this question. Data of 32 participants, to whom it also was applicable, is missing, because the individuals didn't want to answer or didn't remember any reasons.

This item was not designed for multiple answers.

About one quarter stayed at home longer out of concern for the participant's physical health. This was especially the case when the journey to school was long or the child was less resilient than others. This applied to 28.6 per cent (4/14) of Non-Attenders and 20 per cent (4/20) of Attenders. When patients missed too much school and could not follow the lessons any more, they stopped attending school. 21.4 per cent (3/14) of Non-Attenders and 20 per cent (4/20) of Attenders confirmed this. The need to relax and recover after a seizure was another reason given by 14.3 per cent (2/14) of Non-Attenders and 25 per cent (5/20) of Attenders for staying at home.

1.9 per cent (1/14) of Non-Attenders and 10 per cent (2/20) of Attenders stayed at home because of a stigmatization. They felt ashamed and also that they were being treated as inferior.

Socio-economic reasons applied to 28.6 per cent (4/14) of Non-Attenders and 10 per cent (2/20) of Attenders. What this meant in detail was that children were needed at home to

care for siblings or help in the fields or watch the cattle and/or the family could not afford to send them to school. Also, there was no money for uniform, books, etc.

Mental impairment had kept 10 per cent (2/20) of Attenders from going to school. They had not reached the necessary intellectual level and a specialised school was not available.

20 per cent (1/20) of Attenders did not remember the reason for irregular attendance at school.

Overall, socio-economic reasons were most apparent in showing the discrepancy between Attenders and Non-Attenders, as more Non-Attenders than Attenders named this as the reason. The other values were distributed quite equally.

A significant difference was not found in Fisher's exact test (p = 0.730).

Table 69: Reasons for irregular attendance*

	Non-Attender	Attender	Total
Fear for physical health of patient	4	4	8
	28.6%	20.0%	23.0%
Stigma	1	2	3
	7.1%	0.0%	8.8%
Patient could not remember	0	1	1
	0.0%	5.0%	2.9%
Social	4	2	6
	28.6%	10.0%	17.6%
Missed too much	3	4	7
	21.4%	20.0%	20.6%
Relax after fit	2	5	7
	14.3%	25.0%	20.6%
Mentally impaired	0	2	2
	0.0%	10.0%	5.9%
Total	14	20	34
	100.0%	100.0%	100.0%

*

	Value	Exact Sig. (2-sided)
Fisher's exact test	4.25	0.730
N of valid cases	34	

*The item would apply to 66 participants, of whom 32 did not want to answer or did not remember.

10.5 Age when starting school

There was no significant difference in the age of participants when they started their school education (p = 0.926).

The mean age overall was 10.8 (SD: 2.01; median: 11.0; range: 6-16) years.

Table 70: Age when school started (yrs.)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	10.9	2.26	11	7	16	39
Attender	10.8	1.74	11	6	15	38
Total	10.8	2.01	11	6	16	77

Mann-Whitney U	732
Asymp. Sig. (2-tailed)	0.926

*The question would apply to 81 patients who visited school. However, four participants did not answer.

11 ECONOMIC ASPECTS

The majority of Non-Attenders stated having an insufficient regular and secure supply of food. Also, Non-Attenders generally practised open defecation in the proximity around their houses as there was no pit latrine available.
Attenders had more frequently some form of mechanised transportation, whereas Non-Attenders had on average slightly more cattle.

11.1 Food security

The process for determining the security of food supply is explained in chapter Methods (II.4.2; page 36).
There was no significant difference between Attenders and Non-Attenders. In both groups the values ‘poor’ and ‘medium’ amounted to over 60 per cent.
8 per cent (5/56) of Non-Attenders were categorised as being ‘very poor’ as well as 4.5 per cent (3/66) of Attenders. The opposite value of ‘very well off’’, was recorded for 5.4 per cent (3/56) of Non-Attenders and 6.1 per cent (4/66) of Attenders. The question was not answered by 10.7 per cent (13/122) of the participants (ten Attenders and three Non-Attenders). The difference was found to be not significant (Fisher’s exact test: $p = 0.581$)

Table 71: Food security

	Non-Attender	Attender	Total
Very poor	5	3	8
	8.9%	4.5%	6.6%
Poor	18	19	37
	32.1%	28.8%	30.3%
Medium	20	23	43
	35.7%	34.8%	35.2%
Good	7	7	14
	12.5%	10.6%	11.5%
Very good	3	4	7
	5.4%	6.1%	5.7%
Not answered	3	10	13
	5.4%	15.2%	10.7%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	3.91	0.581
N of valid cases	122	

11.2 Defecation management

The question was, what kind of toilet the interviewed person normally used or respectively which sort of toilet was built in their homes.

The most common type was the "pit-latrine". 67.9 per cent (38/56) of Non-Attenders and 75 per cent (50/66) of Attenders gave this answer. With both groups it was seldom that a water closet was installed in the house. Only 8.9 per cent (5/56) of Non-Attenders and 6.1 per cent (4/66) Attenders homes had such a facility.

There was a remarkable gap between Attenders and Non-Attenders, concerning the practice of defecating in the bush. This was practiced by 19.6 per cent (11/56) of Non-Attenders but only by 4.5 per cent (3/66) of Attenders.

Nine per cent (11/122) did not answer this question.

In the Fisher's exact test this difference was found to be significant ($p = 0.017$).

Table 72: Defecation management

	Non-Attender	Attender	Total
Bush	11	3	14
	19.6%	4.5%	11.5%
Pit latrine	38	50	88
	67.9%	75.8%	72.1%
WC inside housing	5	4	9
	8.9%	6.1%	7.4%
Not answered	2	9	11
	3.6%	13.6%	9.0%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	9.89	0.017
N of valid cases	122	

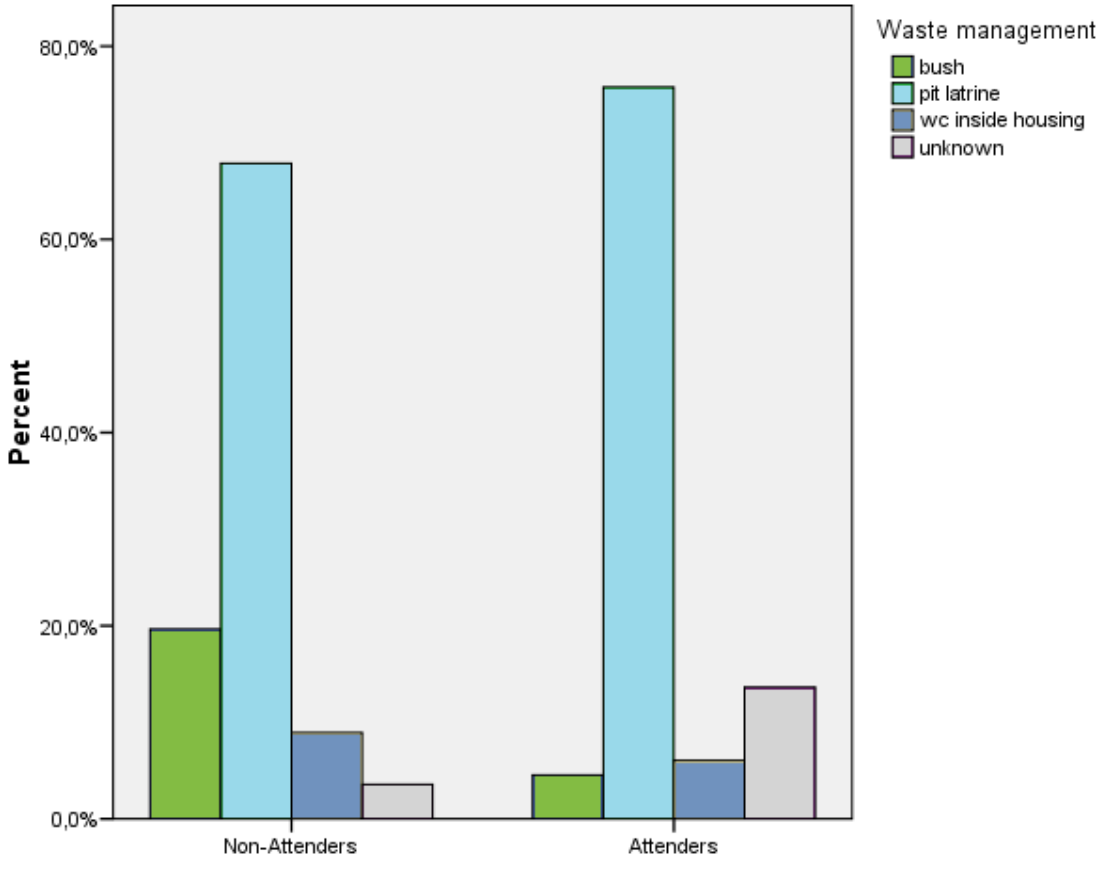

Figure 10: Defecation management

11.3 Distance to potable water

Concerning access to drinking water there was very little discrepancy between Attenders and Non-Attenders. Most participants, 80 per cent of Non-Attenders and 67 per cent of Attenders, had a traveling time for catching potable water ranging from less than 15 min to less than 60 min to the nearest water source.

7.1 per cent (4/56) of Non-Attenders and 12.1 per cent (8/66) of Attenders had a traveling time of more than 60 min. 5.7 per cent (7/122) of the participants had a water tap inside of the housing. 11.4 per cent (14/122) did not answer this question.

The Fisher's exact test showed no significance (p = 0.535).

Table 73: Distance to potable water

	Non-Attender	Attender	Total
>60 min away	4	8	12
	7.1%	12.1%	9.8%
<60 min and >15 min away	28	28	56
	50.0%	42.4%	45.9%
<15 min away	17	16	33
	30.4%	24.2%	27.0%
Inside housing	3	4	7
	5.4%	6.1%	5.7%
Not answered	4	10	14
	7.1%	15.2%	11.5%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	3.25	0.535
N of valid cases	122	

11.4 Water source

This item also revealed no difference between Attenders and Non-Attenders.

Overall the numbers are quite similar; slightly more Attenders used water pumps compared to Non-Attenders, whereas more Non-Attenders fetched water from a river or lake than Attenders. Data for five of 122 participants (4.1 per cent) is absent, because the patients did not answer the question.

There was no significant difference in the Fisher's exact test (p = 0.784).

Table 74: Water source

	Non-Attender	Attender	Total
River / lake	35	36	71
	62.5%	54.5%	58.2%
Deep well	1	1	2
	1.8%	1.5%	1.6%
Water pump	16	22	38
	28.6%	33.3%	31.1%
Tap	3	3	6
	5.4%	4.5%	4.9%
Not answered	1	4	5
	1.8%	6.1%	4.1%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	2.15	0.784
N of valid cases	122	

11.5 Quantity and sort of mechanized transportation

Overall more Non-Attenders than Attenders had no form of mechanized transport whatever. Participants belonging to the group of Non-Attenders more often had to reach the clinic on foot (or mount a bicycle) or had to borrow some other form of transportation. More than twice as many Attenders, compared with Non-Attenders, had even more than one bicycle available. 10.7 per cent (13/122) did not answer this question.
In the Fisher's exact test no significant difference was found (p = 0.328).

Table 75: Transportation mechanized

	Non-Attender	Attender	Total
No bike, no car	33	30	63
	58.9%	45.5%	51.6%
One bike	16	19	35
	28.6%	28.8%	28.7%
More than one bike	2	5	7
	3.6%	7.6%	5.7%
Car	2	2	4
	3.6%	3.0%	3.3%
Not answered	3	10	13
	5.4%	15.2%	10.7%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	4.66	0.328
N of valid cases	122	

11.6 Family's number of cattle

Non-Attenders owned both more cows and goats than Attenders. The difference, however, was minimal in both cases.

A Non-Attender possessed, on average, 5.31 (SD: 7.27; median: 3.0; range: 0-38) goats, an Attender 5.03 (SD: 4.49; median: 5.0; range: 0-20) goats.

A Non-Attender possessed, on average, 7.36 (SD: 10.2; median: 4.0; range: 0-50) cows, an Attender 6.48 (SD: 9.58; median: 4.0; range: 0-50) cows.

There was no significant difference using the Mann-Whitney U test with regard to the numbers of cows ($p = 0.782$) and goats ($p = 0.366$) each possessed.

Table 76: Number of goats*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	5.31	7.27	3.00	0	38	55
Attender	5.03	4.49	5.00	0	20	61
Total	5.16	5.95	4.00	0	38	116

Mann-Whitney U	1517
Asymp. Sig. (2-tailed)	0.366

*Six participants did not answer this question

Table 77: Number of cows*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attender	7.36	10.2	4.00	0	50	55
Attender	6.48	9.58	4.00	0	50	61
Total	6.90	9.837	4.00	0	50	116

Mann-Whitney U	1628
Asymp. Sig. (2-tailed)	0.782

*Six participants did not answer this question

12 RETROSPECTIVE ANALYSIS OF FORMERLY COLLECTED DATA OF THE STUDY POPULATION

Previous data from the patients of this study was available, as they were part of a population (=source population) which was examined before. Therefore, there was a possibility of a retrospective analysis of the data. More details are described in chapter Methods (II.3; page 27)

Data of the source population was, according to Kolmogorov-Smirnov-test, mostly distributed non-parametrically. Merely, “age at presentation”, “age at marriage” and “age at school-start” were distributed normally, with a significance of more than 0.05 in Kolmogorov-Smirnov- test.
An explanation why “age at presentation” was distributed normally within the source population, but was not within the data of the main study (collected about five years later), might be that the people in these rural areas have a totally different concept of time and most of them do not know an exact birthday. Thus, this item cannot be deemed as exact as it would be in western countries.
The three normal distributed items were analysed by T-test and the others by Mann-Whitney-U testing and Pearson-χ^2-test or Fisher’s exact test for categorical data. The statistical significance was set at 0.05 again.
The following table shows the retrospectively analysed variables after sorting the patients of the source population into Attenders and Non-Attenders:

Table 78: Analysed items of the formerly collected data within the source population comparing Attenders and Non-Attenders and test concerning statistical significance

Categorical data	**Pearson Chi-Square test (p)**	**Fisher's exact test (p)**
Severity of injuries when having seizures		0.31
Marital status	0.39	
Patient on anti-epileptic medication at the time of registration		***0.02***
Reduction of seizure frequency on current medication	0.35	
Satisfactory response on treatment		0.56
Side effects	0.52	
Patient has tried herbal treatment		0.34
Patient has tried scarifications	0.55	
Family history of epilepsy		***0.04***
Place of delivery		0.37
Type of medication on discharge	0.38	
Patient addicted to alcohol		0.25
Patient drop out of follow-up		***0.00***
Pubescent patient	*0.07*	
Continuous data	**T-test (p)**	**Mann-Whitney U test (p)**
Age at registration	*0.22*	
Duration of motor signs		0.63
Frequency of seizures before treatment		0.21
Frequency of seizures after treatment		0.53
Age at first fit		0.53
Age at diagnosis		0.60
Number of own children		0.64
Age at school-start	0.41	
Age at marriage	0.11	
Distance to hospital (HLH)		***0.03***
Total number of animals		0.24

Comparing Attenders‘ and Non-Attenders’ data, it became apparent that several items showed significant statistical differences.

Within the table, significant differences relating to statistics are marked as italic and bold, and those with a statistical strong tendency are marked as italic.

The differences between Attenders and Non-Attenders could help identifying patients vulnerable to non-adherence at registration or within the course of the first follow-ups.

More precisely elucidated are the items with a statistical significant difference or a statistical tendency.

12.1 Patient on anti-epileptic treatment at the time of registration

Patients who were already on some AED at the time of registration were more likely later on to be adherent to treatment and medication. 71.2 per cent (47/66) of patients classified as Attenders were already on anti-epileptic treatment, while only 51.8 per cent (29/56) of Non-Attenders did so at registration. This difference was statistically significant, p = 0.02.

Table 79: Patient is on anti-epileptic treatment

	Non-Attenders	Attenders	Total
no	27 48.2%	19 28.8%	46 37.7%
yes	29 51.8%	47 71.2%	76 62.3%
Total	56 100.0%	66 100.0%	122 100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	4.88	0.022
N of valid cases	122	

12.2 Family history of seizures

If there was a history of epilepsy within the family of the patient, more often non-adherence would prevail. Patients later classified as Non-Attenders had, with 41.1 per cent (23/56), more often family-members also affected with epilepsy than these patients who were classified as Attenders (24.2 per cent; 16/66). This discrepancy was affirmed by a statistical difference with p = 0.04.

Table 80: Family history of seizures

	Non-Attenders	Attenders	Total
no	33	50	83
	58.9%	75.8%	68.0%
yes	23	16	39
	41.1%	24.2%	32.0%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	3.95	0.037
N of valid cases	122	

12.3 Patient drop out of follow-up

As a percentage, more than twice as many patients of later classified Non-Attenders were already labelled as "drop-outs" during the observation of the attendance of first follow-ups. In numbers, these were 46.4 per cent (26/56) Non-Attenders compared to 21.2 per cent (14/66) Attenders. This difference was found highly significant in Fisher's exact test; p = 0.00.

Table 81: Patient drop out of follow-up

	Non-Attenders	Attenders	Total
no	30	52	82
	53.6%	78.8%	67.2%
yes	26	14	40
	46.4%	21.2%	32.8%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Fisher's exact test	4.65	0.003
N of valid cases	122	

12.4 Frequency of seizures before and after treatment

Data of 97 participants (frequency before) resp. 57 participants (frequency after) was available.

The retrospective analysis of the frequency of seizures before and after the anti-epileptic treatment held an interesting difference, even if it was statistically not significant.

In fact, patients later grouped as Non-Attenders had on average a higher frequency of seizures before treatment, 10.0 (SD: 29.8; median: 3; range: 0.1-75) per month. Concomitantly, their seizures seemed to respond well to AED, as the frequency of seizures after start of treatment was quite low with 1.11 (SD: 1.80; Median: 0.1; range: 0.0-7.5) per month. Thus, there were nearly nine seizures in average less per month.
Attenders had a minor difference in frequency of seizures before and after treatment. The difference was 6.1 seizures less per month after starting medical treatment.

Table 82: Frequency of seizures before treatment (per month)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attenders	10.0	29.8	3.00	0.1	75.0	42
Attenders	8.78	16.8	3.50	0.1	180.0	55
Total	9.39	23.3	3.25	0.1	180.0	97

Mann-Whitney U	985
Asymp. Sig. (2-tailed)	0.213

*Data of 25 patients is missing

Table 83: Frequency of seizures after treatment began (per month)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attenders	1.11	1.80	0.1	0.0	7.5	24
Attenders	2.61	11.4	1.0	0.0	75.0	43
Total	1.68	6.58	.55	0.0	75.0	57

Mann-Whitney U	461
Asymp. Sig. (2-tailed)	0.528

*Data of 55 patients is missing

12.5 Age at registration

There was a difference between Non-Attenders and Attenders concerning age, corresponding to the main study. However, the difference was somewhat larger, with Attenders being about three years older than Non-Attenders (in the main study 2.2 years). Here Non-Attenders were on average 20.0 years (SD: 12.9; median 19.5, range: 0.5-67.0) and Attenders were on average 23.0 years (SD: 14.2; median: 21.0; range: 1.2-65) at registration.

The difference in age (around twenty) therefore is meaningful, as it affected just the transition from childhood to adulthood. There was no statistical significance.

Table 84: Age at registration (yrs.)

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attenders	20.0	12.9	19.5	0.5	67.0	56
Attenders	23.0	14.2	21.0	1.2	65.0	66
Total	21.5	13.6	20.3	0.9	67.0	122

T-test	0.22
N of valid cases	122

12.6 Pubescent patient

As betokened by the previous item, comparing adolescents in pubescent age (determined from 10 to 20 years), apparently more Non-Attenders were in this complicated period of life. There were nearly half of the Non-Attenders (48.2 per cent; 27/56) compared to 31.8 per cent (21/66) Attenders pubescent.

This difference was almost significant in Pearson Chi-Square test (p = 0.065).

Table 85: Patient in pubescent age

	Non-Attenders	Attenders	Total
No	29	45	74
	51.8%	68.2%	60.7%
Yes	27	21	48
	48.2%	31.8%	39.3%
Total	56	66	122
	100.0%	100.0%	100.0%

	Value	Exact Sig. (2-sided)
Pearson Chi-Square test	1.43	0.065
N of valid cases	122	

12.7 Distance to Haydom Lutheran Hospital

Data of 114 participants was available.

The distance to HLH was already a prominent and statistically significant item in the main study. Here, the difference was somehow even wider at about 12.3 km more, which Non-Attenders had on average to travel, for visiting the HLH. In the main study the difference was in mean 11 km.

In statistics was found a significant difference; p = 0.03.

As no exact signposting exists in this rural region of Tanzania and some access to a village seemed to be cross-country, the discrepancy in the statement of distance seems plain.

Table 86: Distance to Haydom Lutheran Hospital (km)*

	Mean	Std. Deviation	Median	Minimum	Maximum	N
Non-Attenders	37.8	37.6	30.0	3	200	53
Attenders	25.5	28.2	20.0	1	170	61
Total	31.6	32.9	25.0	1	200	114

Mann-Whitney U	1225
Asymp. Sig. (2-tailed)	0.026

*Data of eight patients is missing

13 SUMMARY OF RESULTS

Reasons for non-adherence:

Most prevalent reasons for Non-Attenders for non-adherence were, there were no more seizures, they were not satisfied with treatment, or the travelling conditions to the hospital were too difficult.

Distance to health facility:

A relevant (and statistically significant) difference was found within the distance to treatment facility, which was longer for Non-Attenders than for Attenders.

Recent medication and frequency of seizures and use of health care:

Non-Attenders mostly were not on AED at the time of the interview as well as at the first visit in the hospital.

Non-Attenders significantly more often had dropped out of follow-ups within the first months after registration.

Family history:

Non-Attender significantly more often had a positive family history concerning epilepsy compared to Attenders.

Non-Attender generally younger and pubescent:

Non-Attenders were on average more than two years younger than Attenders. Conspicuously more Non-Attenders than Attenders were pubescent.

Socioeconomic aspects:

More Non-Attenders than Attenders stated having an insufficient and irregular supply of food. Additionally, significantly more Non-Attenders had no pit latrine available which indicates a more traditional way of life. Attenders had more often access to some form of mechanised means of transport.

School attendance:

Attenders attended school more regular than Non-Attenders who mostly gave socio-economic reasons for their lack of attendance.

Alcohol:

Non-Attenders began consuming alcohol at a younger age. Their current drinking habits, however, differed only marginally from those of Attenders.

Difference in attitudes towards the disease:

Non-Attenders thought of themselves as being more efficient regarding their work performance than Attenders did. Nevertheless, proportionally more than twice the number of Non-Attenders stated that they were coping less well with their epilepsy than Attenders did.
More Non-Attenders than Attenders were certain that others were not noticing their epilepsy.

IV. Discussion

1 Methodological issues

Cultural issues

Absent infrastructure caused many problems. Additionally, electricity blackouts, breakdowns of the vehicle, diseases of the assisting personnel, religious holidays and fatality in the assistant's family led to delays.

On several occasions the African concept of "time" led to misunderstanding and missing patients. It can further be assumed that some information was lost in translation between English and the respective native language.

Difficulties in data collection

Questions concerning alcohol, sexuality, marital problems or abuse were generally a difficulty and answered satisfactorily rather as an exception, although the questions were put in a sensitive manner. Particularly women often just said nothing or chuckled timidly. Statements of addiction, marital problems or abuse therefore must be rated as underestimated.

The lack of private space during the interviews was problematic. Some questions (regarding the community) would probably have been answered differently if the patient has not been surrounded by members of family and/or neighbourhood. However, this situation could not always be prevented.

Selection of the study population

Despite careful sampling of the study population, in the end more patients were included who were living more closely to the HLH. The difference to the patients of the source population, they derived from, was averaged 11.7 km. Patients who could not be located (27 persons) contributed most to this difference. Some patients lived at a distance of 120 km from the HLH (resulting in a travel time up to six hours). Apart from two occasions, it was usually not possible to stay overnight in a village. Is was hardly possible to conduct time-consuming searching for those living remotely multiple times. Also, if the patients were at work in the fields ("shamba"), not in every situation could be waited for their return, as the long ride back to the HLH at night would be jeopardous. On the other hand, patients living nearby could be examined almost completely in a relatively short time frame. This effect most likely caused an underestimation of the average travel distance of the Non-Attenders.

Psychiatric assessment

As the psychiatric assessment was performed by medical students with limited experience and also because of cultural peculiarities data might be biased.

2 DEMOGRAPHICS

2.1 Gender

In this study population, males outnumbered females in terms of gender-ratio. Out of 122 participants 44.4 per cent (54/122) were females and 55.7 per cent (68/122) were males. The slight preponderance of males was apparent in both groups, it was higher in Non-Attenders (males: 58.9 per cent; 33/56) than in Attenders (males: 53.0 per cent; 35/66). As outlined in a review by Jallon (1997), in developing countries male individuals are more often afflicted with epilepsy than females (Jallon, 1997).

The gender ratio within the group of Attenders was similar to the cohort they derived from (the entity of 337 patients registered in 2004), which was 52.2 per cent (176/337) male patients.

The greater preponderance of males within the group of Non-Attenders as result of our study relates to the generally worse health care utilisation by men and the careless male behaviour towards adherence and preventive medical check-ups, frequently specified in literature. Most researchers stated females to have better adherence (WHO, 2003; Jin et al., 2008).

2.2 Age

In literature a correlation was mainly found between age and non-adherence. According to Jin and colleagues, the effects of age can be divided into three groups: adherence in the elderly, in the middle-aged, and in the adolescents (Jin et al., 2008).

For elderly people, the results from the various studies were inconclusive. Middle-aged patients were most likely to be compliant to therapy. In adolescents and children with chronic diseases the lowest compliance occurred (WHO, 2003).

This corresponds to the findings of this study. Non-Attenders were on average 2.2 years younger than Attenders. Among the patients of the source population, pubescent teenagers formed nearly one half of the group of Non-Attenders (48.2 per cent; 27/56), whilst there were less than one third teenagers within the group of Attenders (31.8 per cent; 21/66). This suggests the impact of puberty and adolescence on adherence-behaviour. During adolescence, individuals want to show and establish autonomy and start to distance themselves from parental generation. This period is often marked by rebellious behaviour and disagreement with parents and authorities (WHO, 2003; Tebbi, 1993; Jin et al., 2008; Eatock et Baker, 2007). Apart from that, non-adherence could be an attempt to negate the disease which is making them different or even less valuable to others in their peer-group

The difference in age probably also had an effect on the results of the items “marital status” and “number of children”.

2.3 Marital status

At the time of the survey, out of 122 participants almost 50 per cent were married, less than two per cent were divorced and one per cent lived separated. Additionally, almost 20 per cent of participants indicated being single and a good 30 per cent were under age of 16. Compared to 62.1 per cent married Tanzanians censed in 2010 (National Bureau of Statistics - Tanzania, 2011), PWE in this cohort were overall less likely to be married. This result corresponds to a study with 169 PWE conducted in rural Zambia also indicating that PWE were less likely to be married or to remain married compared to a control group (Birbeck, 2000). The number of divorced, separated or widowed PWE in the Zambian study was with 28 per cent but larger than in our study. Another study conducted in Cameroon showed an even bigger difference in comparison of marital status of PWE to a control group. Only 20.9 per cent of women (compared to 65.1 per cent of the control group) and 12.8 per cent of men were married (compared to 53.2 per cent of the control group) in this study (Preux et Druet-Cabanac, 2005).

In our study Non-Attenders were less often single and more often under age and thus labelled as “child”. The diagnosis of ‘epilepsy’ was a hindrance to marriage for 17.2 per cent of Non-Attenders and almost 30 per cent of Attenders, the difference in this item may be due to the age-difference. The rest of the patients had personal reasons for not marrying or has been divorced before.

Literature indicates that marital status influences patients’ adherence positively due to the help and support of the patient’s spouse (Modi et al., 2011; Getachew et al., 2014; Elliotta et al., 2011).

Contrary to that, we found no correlation between marital status and adherence. Moreover, we found a tendency of unmarried, “single” PWE (almost 70 per cent) being more often Attenders than married individuals (a good 50 per cent).

The question about “marital problems“ was affirmed by more Attenders than Non-Attenders: 13.8 per cent of Non-Attenders vs. 31.3 per cent of Attenders admitted problems. A considerable number of participants chose not to answer this question, one half of the Non-Attenders and 25 per cent of the Attenders. The difference may suggest that Non-Attenders were less open to investigation than Attenders were, or that they wanted to conceal marital problems.

Also, the question on polygamy, which is legal in Tanzania (Emory law, 2012) and especially common in rural areas, remained unanswered by more Non-Attenders than Attenders, namely 31.0 per cent versus 21.9 per cent. Living polygamous was supported by 27.6 per cent of Non-Attenders and 21.9 per cent of Attenders. This may be an indication for a more traditional lifestyle of Non-Attenders.

While within the item of “the mean age at first marriage”, there was no remarkable difference between both groups, - there was a noticeable difference in the mean differences of age between female participants and their spouses:

In female married or once-married Attenders the mean difference in age (to their spouses) was 9.49 years, whereas it was clearly more in female Non-Attenders, namely 15.5 years. An educated guess would be that Non-Attenders were wed to older men, as it is common in a more traditional environment, maybe to get a bride price although the girl suffers from epilepsy.

2.4 Number of children

Non-Attenders had fewer children both dead and alive. The mean number of own children living was 2.26 and for children deceased 0.4. Attenders had an average of 2.52 children living and 0.6 children deceased.

The average fertility concerning Tanzanian women is 2.4 children and on average 0.4 deceased children (National Bureau of Statistics - Tanzania, 2011). The numbers are similar to those we found. The smaller number of children (dead and alive) in Non-Attenders probably can be traced back to their younger mean age.

2.5 Cohabitating people

The number of cohabitating people at their homes, was almost equal in Non-Attenders and Attenders. There was an average of 7.1 people living together with the family of the participant. The mean number was noticeable higher than the average household size reported by the census 1978 - 2012 established in 2002 indicating that 4.9 persons lived in one household in rural areas. (National Bureau of Statistics - Tanzania, 2006)

Most of the participants (around 90 per cent in both groups) stayed with their nuclear family.

2.6 Religion and occupation

The CIA-fact book (and several other sources with similar numbers) shows that in the mainland of Tanzania about 30 per cent were Christians, 35 per cent Muslims and 35 per cent of indigenous beliefs (CIA, 2012).

The percentages differ presumably between the regions of Tanzania. In a study conducted in the south of Tanzania Moslems outweighed Christians and only a minority practised traditional animist religions. In contrast to that, within our study cohort Christians dominated others by far with overall 80 per cent, followed by 15 per cent indigenous believers and one per cent Muslims. Most people, namely 42.6 per cent (52/122), supported the Lutheranism, probably because of the great impression the founders of the Lutheran hospital had left. The "Catholic" and "Pentecostal" Christian followed in numbers with 19.7 per cent (21/122) and 17.2 per cent (18/122), respectively.

A slight influence of religion was discernible. PWE belonging to Pentecostal or Catholic secession were more regularly attending the clinic (Catholic Non-Attenders: 17.2 per cent vs. Attenders: 21.2 per cent. Pentecostal Non-Attenders: 10.7 per cent vs. Attenders: 22.7 per cent). A potential reason could be the religious influence on lifestyle and the greater obedience demanded by religion. The passion displayed in practicing the religion might also lead to more strictness and regularity in attending the appointments. However, these were only small numbers and no statistical significance was found. The difference can solely be described as a slight tendency.

Similarly, also the differences in occupation between Attenders and Non-Attenders were not significant. Most of the adult participants of both groups (in mean 63.9 per cent) declared to work as farmers. This largely corresponds with the census of 2010, in which in rural mainland of Tanzania about 80 per cent indicated to be farmers (National Bureau of Statistics - Tanzania, 2011).

2.7 Distance to Haydom

The average distance to Haydom was 11 km more in the Non-Attenders' group than in the Attenders' group. Being a significant difference, it can be seen as the main reason to stop the follow-up at HLH. The average one-way-distance to cover to HLH was 41 km for Non-Attenders compared 30 km for Attenders; thus 11 km more in Non-Attenders.

Within the data of the source population the difference in distance was even larger namely 12 km.

The negative effect of a long distance to the health care centre is well known and its impact on the possibility to practise adherence was described frequently in literature and was shown

in other studies and reviews of literature dealing with adherence-behaviour (WHO, 2003; Bernhanu et al., 2009). The effect applies especially to low income countries. A study conducted in Ethiopia in 2000 (Bernhanu et al., 2009) dealing with causes of default from follow-ups at an epilepsy clinic in a rural area, brought similar results as our study. The most common reason in this study to stop the follow-ups was the distance to the health centre. The severe influence of a long distance from the area of living to treatment setting is also mentioned in the review concerning non-adherence by the WHO (WHO, 2003) as a limiting socioeconomic related factor (see introduction). Among various studies on different diseases conducted in developing countries, the difficulty of long distances to health facilities was found an important factor influencing adherence. Not only that patients have to overcome a usually burdensome trek, they also have to raise the money for transport costs and the non-productive time. Families have to solve logistic problems to accompany a patient to the clinic.
In the item „reason for non-attendance" the problem is reflected in the second most answer of the participants (after "no seizures anymore"): "rough and/or costly journey".
Furthermore, even the distance to the next dispensary was on average somewhat longer in Non-Attenders than in Attenders. On average, Non-Attenders lived 11 km and Attenders 9 km away from the next dispensary.
Overall, these findings suggest that Non-Attenders are living more remotely. However, approximately 20 per cent of Non-Attenders got AED from a dispensary. The system of decentralized dispensaries seems advantageously, but AEDs are not available in every dispensary. One quarter of Non-Attenders reported that there were no AEDs distributed at their dispensary.
Concerning this item, it should be kept in mind that distance most probably in Non-Attenders is biased and even underrated. This fact is explained within the subchapter 'methodological issues' (IV.1, page 123f). More patients living closer to the HLH had been interviewed. Especially Non-Attenders living very far away (up to 120 km distance to HLH) and remote could not be searched for excessively, for organisational reasons.

2.8 Mortality

Generally, mortality is known to be higher among PWE than in normal population (Forsgren et al., 2005). Literature states that this is connected to low income as well as high income countries (Diop et al., 2005). However, in low income countries the mortality of PWE is regularly found noticeably higher than in high-income countries (Panayiotopoulos et al., 2010; Diop et al., 2005; Senanayake et Roman, 1993). This fact was pictured very explicitly by Diop and colleagues in a review of literature. He found mortality among PWE in

developing countries being up to six times higher than in developed countries. As most frequent causes of death he lists status epilepticus, sudden unexplained death in epilepsy, and drowning (Diop et al., 2005).

An increased risk of early death in people with active epilepsy was demonstrated in this small sample.

In our study (at least after the existing data) we found that Non-Attenders had a higher mortality than Attenders. This result would seem comprehensible and is consistent with the observations of Berhanu and colleagues, who described in a study that the mortality of patients who defaulted from follow-ups at an epilepsy clinic in Ethiopia was shown to be higher than of those who did follow-ups regularly (Berhanu et al., 2009). Unfortunately, it has been much more difficult to get data of the deceased than of living patients. There remained gaps and uncertainties to an extent that purposeful evaluation was not possible.

In any case, the number of dead patients is presumably underrated. Some of the patients who could not be met at their homes and of whom no further information existed, might also have passed away.

3 DIAGNOSIS AND SEIZURE HISTORY

The classified diagnosis did not seem to have an impact on adherence-behaviour. There was no significant difference nor one by trend between the groups of Attenders and Non-Attenders.

Of 122 patients of our cohort 55 per cent were classified as having “primary generalised epilepsy”, thus being the most frequent diagnosis. Seizures were exclusively of the grand-mal type which leads to the presumption that more discretely passing seizures, for example focal seizures, may not be identified as an epilepsy.

Data concerning seizure frequency in developing countries is scarce. Rwiza and his colleagues (Rwiza et al., 1993) found in their study a median frequency of 14 per year. With our patients it was more reasonable to state the frequency in seizures per month as they reported more frequent seizures. Within the six months prior to our survey the median frequency was 2.0 per month in Attenders. Among Non-Attenders it was 4.7 per month, what meant several seizures per week.

Before having started treatment (concerning treatment in HLH), the frequencies in Attenders and Non-Attenders were more similar and averaged to 16.6 per month. More than 98 per cent of our patients had more than one seizure per month before having started treatment. These were significantly more compared to only 38.4 per cent of the patients in the study done by Rwiza et al. who had more than one seizure per month before treatment (Rwiza et al., 1993)

Significantly lower and thereby markedly different was the recent frequency of seizures of Attenders. They reported of 2 seizures per month whereas Non-Attenders reported of 4.7 per month. This shows a significant amelioration, most probably resulting from regular intake of AEDs, by more than 90 per cent of Attenders.

However, the frequency of seizures had decreased compared to the frequency without treatment. More than 40 per cent of Non-Attenders even stated, having had no seizures for more than one year. An explanation might be a favourable natural course of the disease.

Interviewing the sample about 4-5 years earlier had yielded somewhat different results: Non-Attenders at that time had reported a higher frequency of seizures before treatment and seemed to show a markedly positive response to medication, as the frequency was quite low after beginning medical treatment (see chapter Results; III.12.4; page 117f). This means, that the Non-Attenders’ frequency of seizures was higher than that of Attenders in the beginning, and was lower than that of Attenders after treatment had started (The frequency of seizures amongst Attenders also was influenced by AED, but not as strikingly as with Non-Attenders).

In literature it is frequently reported that a higher activity and felt symptoms of a chronical disease would lead to a generally better adherence behaviour than diseases with a benign course (WHO, 2003). This fact can be accepted as true for a part of those patients who did not return for further treatment. On the other hand, “dissatisfaction with treatment” was specified as a major reason for default. Hence, some Non-Attenders seemed to rather accept a high frequency of seizures than to search for assistance.
An explanation for that behaviour could be, that treatment showed no sufficient effect, as well as a feel of despair and hopelessness that there is anything that could improve the situation. Carter et al. picture this behaviour in their study on defaulters conducted in a province of Kenia. He points out the demand for an ultimate healing which also often arose during our interviews with patients and relatives. Even though it was well explained to the patients when diagnosed with epilepsy that AED should be taken over a long period of time, the wish persisted that by taking AED once or only a short period of time healing can be achieved so as to be normal (Carter et al., 2012).

Although depression is seen as an important reason for non-adherence, no such reason was found in our results. Depression or other psychiatric diseases did not play a significant role in our cohort.

Analysing the data of the source population, a significant difference was found between Attenders and Non-Attenders concerning a positive family history of seizures respective epilepsy. Interestingly, by far more Non-Attenders (41.1 per cent) than Attenders (24.2 per cent) had relatives who suffered from seizures too. This phenomenon could not be found in literature. Diverse explanations come into consideration. On the one hand, a family afflicted with plural members who suffer from epilepsy (probably several generations are affected) might be economically weakened. Additionally, the family might be exceedingly stigmatized. Both could be reason to stop visiting the hospital.
Also, it was possible, PWE coming from a family with multiple affected members, feel rather resigned, not believing that treatment could bring relief anyway. Especially when they experienced numerous setbacks concerning the course of epilepsy in relatives.
A more optimistic explanation could be that PWE with positive family history already had access to a health facility and had learned to integrate the disease into daily life.

4 CONSUMPTION OF ALCOHOL

Alcohol consumption is common in Tanzania and an increasing problem in rural areas. Several times we became witnesses of evening gatherings of men and women of different ages consuming alcoholic beverages. Alcoholic beverages play an important role in the people's daily, social, and cultural life. The mean alcohol consumption in Tanzania is higher than in the five adjacent countries (see map by WHO, 2004)

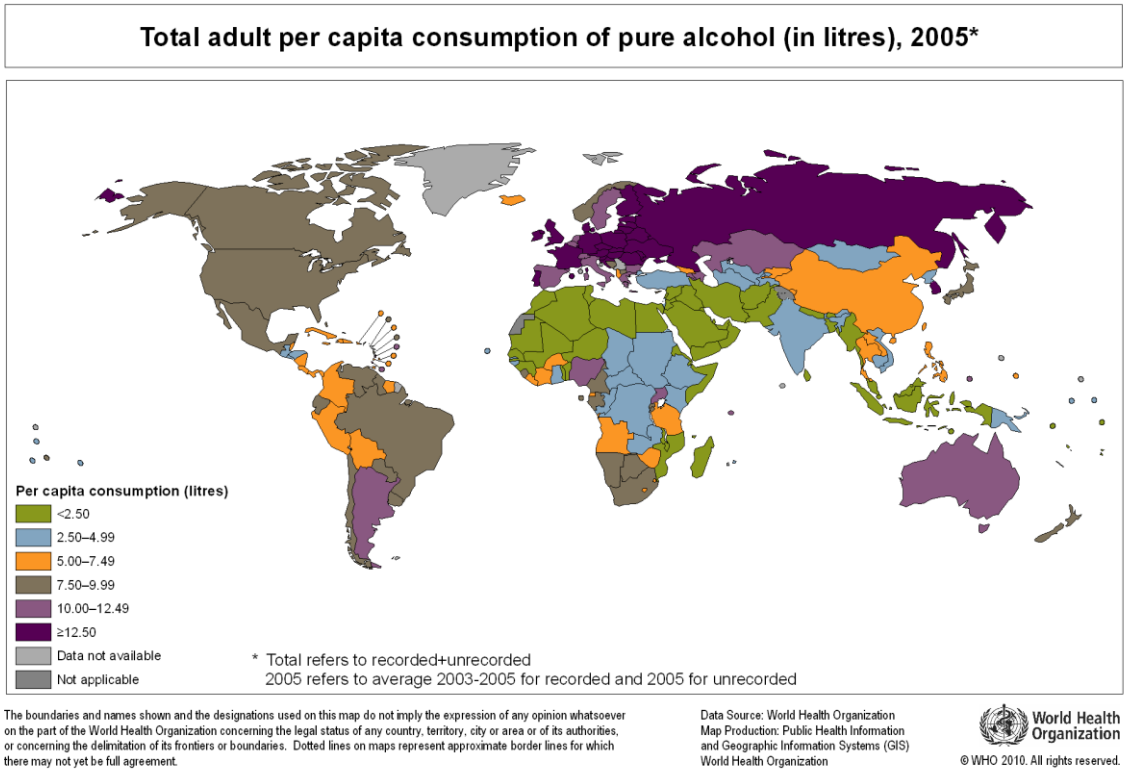

Figure 11: Total adult per capita consumption of pure alcohol

As bottled beer is expensive, there are a lot of 'homemade' drinks. The most common beer according to our patients is made from maize, known as pombe in Kiswahili. Also, kimpumu, a porridge-like millet beer, drunk through a straw, was named quite often.

Continuous drinking of these uncontrolled and noxious substances and methanol spoiled beverages is a risk to people's health (WHO, 2004). But not only are the immediate toxic components a health-hazard. There is a strong relationship between alcohol consumption and an increased risk of epilepsy. Chronic alcohol consumption affects the structure and function of the CNS in different ways. It can lower the epileptogenic threshold, can lead to brain damage resulting in cerebral atrophy. Being drunk the probability to fall increases, so epileptogenesis can also be explained by lesions due to head traumata. Changes in the

transmitter system and ionic imbalances also contribute to a higher risk of seizures or irreversible development of an epilepsy. It is obvious, that heavy alcohol consumption worsens the clinical course of an existing epilepsy by influencing the clearance-rate of AEDs and by an increasing non-compliance to treatment regime (WHO, 2004).

There seems to be only scarce knowledge of risks and hazards of an addiction. A study conducted by Kiangi and colleagues shows, that particularly young people have no access to information concerning substances causing addiction. Besides, young people in rural areas are profiting from producing alcohol and embrace it as a most welcome side-line (Kiangi et al., 1995).

The number of alcohol-addicted Tanzanian people was examined in several studies. The WHO officially indicated the following number of frequent drinkers: 20 per cent male and two per cent female individuals were drinking on five or more days per week (WHO, 2004) . This most likely is an underestimation.

We expected that a considerable proportion of our patients would be drinking alcohol regularly and so experience aggravation of alcohol related seizures or their epilepsies. A survey, anonymously conducted in the Out Patients Department of HLH (before 2005), found out that more than 70 per cent of a cohort of a few hundred patients consumed alcohol regularly. However, only 8.2 percent of patients of our study population admitted to regular or daily drinking. One can assume, that this number is underestimated.

Several studies about compliance in patients with chronic diseases are showing that patients who were smoking or consuming alcohol were more likely to be non-compliant (Jin et al., 2008).

There was a significant difference between Attenders and Non-Attenders regarding alcohol consumption. The latter generally drank more often and more regularly and had begun to drink at a significantly younger mean age. The mean age at which Non-Attenders began to consume alcohol was almost four years lower than the Attenders' mean age. This difference in age is significant (see chapter Results; III.4.2; page 65f).

Within the group of Attenders there was a trend that more individuals had stopped drinking (after formerly drinking regularly). This behaviour correlates with a more health orientated behaviour, which was shown by the Attenders in other aspects, too (e.g. use of healthcare services, adherence to Haydom Lutheran Epilepsy Clinic).

5 TREATMENT

5.1 Antiepileptic treatment in developing countries

There is a manual for African medical clinical officers, which describes the procedure concerning anticonvulsive medication. This booklet advises to begin AED treatment, when at least one confirmed seizure has occurred (Dekker, 2002) which is in line with the ILAE guidelines (Glauser et al., 2006). The aim is to avert further seizures or at least to reduce seizure frequency and severity.

Four major AEDs are indicated as most relevant: Phenobarbitone (PB), Phenytoin, Carbamazepine (CBZ) and Valproate (VPA) (Preux et al., 2000). Nowadays, PB is rarely prescribed in US and Europe because of side effects, but it is still an effective and inexpensive drug.

5.2 Antiepileptic drugs used by patients of our study population

Among patients of our cohort CBZ and PB were currently being used as AED. It seems that in this region the more expensive (PB : CBZ = 1.00 : 4.89 (Dekker, 2002)) but better tolerated CBZ is widespread – it was taken by 63.3 per cent (38/60) of the Attenders. It was the only drug, that 40 per cent (4/10) of the Non-Attenders, who took AED and were able to recall its name, were receiving from dispensaries or other sources.

31.7 per cent (19/60) of the Attenders were treated with PB. In general, monotherapy was the only method applied.

Several patients could not recall the names of neither the current nor the former AED, among Non-Attenders, the number of people not recalling the names was higher. But even there it was confirmed to be a monotherapy. Half of the Non-Attenders that remembered their last medication prescribed by HLH named CBZ and the other half named PB.

Modern drugs, that are prescribed in industrialised countries are to a large extend unknown or too expensive (some prices differ by a factor of 80) in Tanzania.

5.3 Antiepileptic medication at the point of registration

For people in Tanzania there are different levels of access to medical treatment, described in chapter Methods (II.2.2, page 25f).

However, not each of the facilities is well versed with the treatment of epilepsy or equipped with AED.

Analysing the data of the source population, it was recapitulated that more than 70 per cent of later identified Attenders were already on medical treatment when they were registered at Haydom Lutheran Epilepsy Clinic. The percentage of deferred Non-Attenders was significantly lower with a good 50 per cent.
It can be interpreted that Attenders generally show a better self-efficacy On the other hand, knowing that Non-Attenders lived more remotely and had a larger distance both to HLH and to the next dispensary, they might have had worse conditions to get medical help.

5.4 Adherence to treatment and medication

While in 2005 Schaffert reported a satisfactory compliance shown by patients of our cohort, this changed quickly and considerably, in the following years. However, Schaffert already had observed an association between poor adherence to medication and drop-out of the follow-up (Schaffert, 2005).
Adherence and taking medication is often equated in the literature. In our cohort indeed the major percentage of those, who did not attend follow-ups also did not take medication. A few of them received medication from other sources, notably from dispensaries.
With Non-Attenders only a fraction of approximately 20 per cent was taking AEDs received from dispensaries or other sources. Among Attenders 90 per cent were taking AEDs. Ten per cent of Attenders were not on medication for various reasons. Nevertheless, the latter went to the hospital on a regular basis.

5.4.1 Reasons to stop taking medication

More than half of Non-Attenders stated, that after taking medication, they did not experience seizures for a certain period of time (some of them did never experience a seizure again). They tended to believe or rather hoped, they were healed and thus stopped medication. 13.0 per cent did not answer the question after reasons to stop taking medication.
As described by Jin and colleagues, patients who had marked improvement in symptoms with the help of treatment usually showed better compliance. (Jin et al., 2008). This fact might explain why over 15 per cent of Non-Attenders were frustrated, as they did not notice any improvement. Only one Non-Attenders reported side effects being the reason for discontinuing treatment. This number appears to be low, particularly as 33 per cent did mention severe side effects during treatment.
This is also in contrast to the general statement in literature, that adverse side effects are being considered as the main reasons for non-adherence to medication (Eatock et Baker,

2007), what is also reported to be true for developing countries (Jin et al., 2008; St Louis, 2009; Elechi, 1991).

5.4.2 Side effects

Adverse effects are common and reported by 40-50 per cent of epilepsy patients receiving AED treatment as monotherapy. Most common are drowsiness, dizziness, fatigue, headache, blurry or double vision, impaired concentration or memory, or incoordination.

The Manual for Clinical and Medical Officers reports on adverse side effects as follows: Drowsiness is named as the main side effect of PB, especially during the first week of treatment, In general, this condition is expected to improve gradually. Hyperactivity and aggressiveness is possible to occur especially among children. It is stated that in the beginning of the treatment with CBZ drowsiness and dizziness can occur. There might also be double vision or ataxia (Dekker, 2002).

The kinds of side effects stated correspond with those mentioned in current literature. To some extent, there were difficulties to describe the symptoms due to different culture and use of the language.

50 per cent of Attenders complained of side effects, but in various manifestations. 10 per cent of Attenders reported severe side effects.

Among Non-Attenders receiving treatment 50 per cent reported side effects. At the time of the study, none of the Non-Attenders reported severe side effects. One possible explanation is, that because of the impossibility to determine serum levels the dosage was being kept low enough for side effects to not appear.

More than 90 per cent of Attenders were on a regular treatment of AEDs at the time of the interview, therefore it seemed that they concerned themselves with AEDs more profoundly and so they were more sensitive to side effects and also able to describe them better.

Non-Attenders apparently accepted even severe side effects during their former treatment. These patients desired complete healing and could hardly imagine taking AED over a long period of time. Some received drugs in dispensaries. However, it can be assumed that patient information about the necessity of taking medication regularly is probably not very extensive. Dispensaries are not specialized in a certain medical sector, but serve the medical sector in general. Furthermore, in dispensaries patients have to pay for their medication.

5.4.3 Decision of nurses

The clinic is run by nurses and in some cases, they decided to discontinue drugs for a variety of reasons. The permanent presence of a medical specialist seems currently a utopian idea, therefore it is necessary that nurses take decisions of that kind as well.

In six cases the nurses decided that the disease no longer required treatment. Two of the cases involved women who were planning to become pregnant and another case suffered from extreme side effects.

5.4.4 The beginning of non-adherence

Elechi for Nigeria and Jin and colleagues in a broad worldwide review found out, that adherence drops quite quickly (Elechi, 1991; Jin et al., 2008). Elechi is using the example of a tuberculosis therapy with a fixed duration: after six months the adherence was 78 per cent after twelve months 68 per cent (Elechi, 1991).

In a study about children with epilepsy conducted in the United States, Modi reports, that non-adherence manifests itself relatively early. He states non-adherence rates of approximately 20 per cent in the first month of therapy, and almost 60 per cent during the first six months (Modi et al., 2011).

Among our cohort there is no data as to when exactly patients refused treatment for the first time. Many patients could not provide exact information and additionally their medical records were not updated regularly.

However, analysing the data of the source population, it became clear, that later identified Non-Attenders mostly were those patients who already had dropped out of follow-ups within the first months after the start of treatment. Namely nearly 50 per cent of Non-Attenders compared to a good 20 per cent of Attenders failed in visiting all follow-ups. The difference was statistically highly significant:

Those patients who showed inconstancy in the very beginning were mostly the same who did not return to Haydom Lutheran Epilepsy Clinic later on.

5.4.5 Discontinuous supply

Mbuba and Newton as well as Chin make out the lack or the discontinuous supply of medication as a factor contributing to the treatment gap (Mbuba et Newton, 2009; Chin, 2012). It is unknown to us whether there were suchlike problems at HLH during our study. The medication is provided on donation basis. As meanwhile the founder gave the clinic to the state of Tanzania, the current situation is not clear. Mbuba and Newton recognise that if the amount of medication dispensed is only sufficient to cover a short period of time (one to three months), as it is practised also in HLH, the patients have to undertake the costly and demanding trip to the hospital quite frequently. This may discourage patients from regular attendance (Mbuba et Newton, 2009).

5.4.6 Natural course of epilepsy

In specialised literature there are voices questioning how the natural course of the disease would proceed whether remission occurs spontaneously or AEDs have a curative role. Some of the Non-Attenders reported currently having more seizures than Attenders, but still less than they had before being registered. There are hints that not every type of epilepsy has to be treated permanently.

Watts published a study on the history of untreated epilepsy in a rural community in Malawi that suggested that the found decrease in number of people with epilepsy over time is due to the natural remission of epilepsy (Watts, 1992). In western countries a study of this kind is problematic for ethical reasons, while in developing countries data can be evaluated retrospectively.

5.5 Traditional treatment

Citing a PWE from a study conducted by Carter and colleagues in Kenya the felt advantages for patients visiting a traditional healer versus a health centre of Western medicine, becomes clear: “When I am at this place [at the traditional healer] I can sit and talk and explain things for many hours. Sitting here is important for healing. It is necessary to do this if you want to be cured (…). I walk here and then return. (…) when I go to Kilifi [hospital], the doctor does not talk to me. He just asks me some few questions and then gives me a paper [prescription].” (Carter et al., 2012)

Traditional methods of treatment are widespread in Tanzania, as they are in other countries of Sub-Saharan Africa (SSA). Carter describes in her study that was conducted in Tanzania that the explanations provided by the traditional healer for the development of epilepsy are in most cases better understood and accepted than the biomedical explanations by PWE and his family. Furthermore, most patients found consulting the traditional healer more comfortable due to the holistic perspective and the longer time given.

In our study area it was reported by PWE already in a former study, that they had applied herbal treatment in various forms of root, bark, leaf powder or cream (Schaffert, 2005). Some had scarifications or performed other ritual procedures to get rid of an evil spirit.

Another study conducted earlier in Manyara region had shown about half of the interviewed people believed in traditional healing methods. Moreover, in this study the population especially believed that epilepsy was treatable or healable by Christian prayers (Winkler, Mayer, Ombay, Mathias, Schmutzhard et Jilek-Aall, 2010). This religious attitude was not present among our study population (or not any more). However, we have not asked explicitly after the belief in healing by Christian prayers.

5.5.1 Herbal medicine

There seems to be a wide variety of herbal medicine that is used for different kinds of applications. Parts of plants should be consumed as powder, tea or processed into a paste or infusion for unction. In some of the plants, there were substances found that can be active against epilepsy.

Preclinical work based on an approach of Schachter suggested that herbal therapies and compounds from plants may yield promising candidates for further clinical development. Herbal therapies might be an inexpensive culturally acceptable treatment (Schachter, 2009).

In Tanzania, Moshi et al. compared the plants that were used by traditional healers as a cure for epilepsy and found out, that some of these plants have anticonvulsive activity, which is confirmed by literature. They also found out, that healers conveyed a good understanding of the aetiology and the manifestations of the disease (Moshi et al., 2005).

In Cameroon, Njamnshi and colleagues found out, that a number of traditional healers cooperated with hospitals referring patients to hospital when indicated (Njamnshi et al., 2010).

5.5.2 Scarification

Basically, the skin is incised with a sharp instrument, e.g. a knife, a piece of broken glass, a stone, or a coconut shell. Sometimes irritation of the cut skin is caused by applying caustic plant juices to form permanent scars. Dark pigments such as ground charcoal or gunpowder may be rubbed into the wound for emphasis. Once healed, these cuts form raised scars known as keloids.

In Togo one study relates the form of scarification with the type of epilepsy diagnosed. It could inform about frequency and type of seizures (Grunitzky et al., 2000). There was but no evidence that such information given by scars was common in our study area.

5.5.3 Traditional treatment used by patients of our cohort

To our surprise Non-Attenders of our cohort were not more inclined to visit traditional healers than Attenders. The question was if traditional treatment had ever been used. Studies from other parts of Tanzania stated rates up to 94 per cent of PWEs' that were in touch with traditional healers (Bondestam et al., 1990). Birbeck and Baskind report in a study conducted in sub-Saharan Africa, that more than 70 per cent of the patients had formerly frequented a traditional healer and received traditional treatment (Baskind et Birbeck, 2005).

Contrary to speculation, in our sample more Attenders than Non-Attenders had tried herbal medicine: 47 per cent of Attenders compared to 30 per cent of Non-Attenders confirmed this. This may suggest that Attenders try harder because they are suffering more by the disease,

e.g. for psychic or social reasons. The application of scarification was similar in both groups; Attenders 21.3 per cent, Non-Attenders 21.5 per cent.

Possibly, Attenders of this cohort were more eager to confront epilepsy and so they put more into motion. Maybe Non-Attenders did just not give all facts.

All in all, the numbers were lower than expected, which may either point to shame or better education of the cohort.

6 ECONOMIC FACTORS AND HEALTHCARE SYSTEM FACTORS

Economy in Tanzania has remained steady for some decades. However, the country is still ranking among the poorest countries in the world despite the grand efforts of President Julius Nyerere in the nineteen-sixties and seventies (Coulson, 2013). In 2011, Gross National Income per capita in Tanzania was US$ 540 as compared to Germany: US$ 44670 or the United States: US$ 50660 (National Bureau of Statistics - Tanzania, 2011).

Of the Tanzanian population 77.4 per cent live in rural and 22.6 per cent in urban areas. In the Manyara region where the study took place, 86.4 per cent of the people live in rural areas (National Bureau of Statistics - Tanzania, 2011). The most frequently named occupation reflects this distribution. The greatest part of interviewed adult patients worked as self-employed farmers and self-sustaining. This is in accordance to official numbers stating 84.8 per cent of the adult population being farmers (National Bureau of Statistics - Tanzania, 2011).

In 2007, 19.1 per cent of rural Tanzanian population had access to a bank or an own bank account (National Bureau of Statistics - Tanzania, 2009). Among the patients of our study banking was largely unfamiliar and unusual. The farmers earned some money by selling cattle or corn or they ran tea rooms etc. for additional income.

As money counts less in these regions economic wealth can hardly be measured by common western standards. It is more important how much cattle and how many children a man has or the position within the village.

As done in governmental surveys, we tried to measure economic status with the help of other aspects like food security, water supply and the distance to potable water, quantity and sort of mechanized transportations, amount of cattle, kind of housing, existence and kind of toilets.

Disparities between Attenders and Non-Attenders became obvious in several socioeconomic items that mostly indicated Non-Attenders living more remotely and traditionally:

The patients' "food security" was estimated by eight per cent of Non-Attenders as "very poor" compared to 4.5 per cent of Attenders, "very poor" stood for normally having only one ordinary meal per day. However, the opposite value of 'very well off', (what meant, there was no trouble at all with their food supply and that they even had a significant amount of edibles available) was chosen by 5.4 per cent of Non-Attenders and 6.1 per cent of Attenders.

Concerning the „defecation management", a statistically significant difference was found. Nearly 20 per cent of Non-Attenders but only by 4.5 per cent of Attenders practised open defecation, because there was no pit latrine or toilet at home.

In rural areas, an average of 87.2 per cent of households own a pit latrine and 9.5 per cent have no toilet (National Bureau of Statistics - Tanzania, 2011). Thus, Non-Attenders even exceeded the national average among rural population. We believe the existence of at least a pit latrine representing an important item reflecting the health-awareness a family has or can have due to their economic status. It was a seminal result finding this significant difference between Attenders and Non-Attenders.

A similar correlation was found concerning the use of healthcare services. It indicated that Attenders generally make more use of medical assistance than Non-Attenders. One could consider that Non-Attenders are healthier people than Attenders, but more likely they are more reluctant looking for help and cannot make the way to a health facility for different reasons.

The distance to potable water and the supply of water showed no significant difference between the groups. However, Attenders had to walk somewhat longer to get water (Non-Attenders: 80.4 per cent < 60 min vs. Attenders: 66.6 per cent < 60 min to walk). As to the source of water there was a higher number of water pumps among Attenders, which implies controllable quality of water, while Non-Attenders more often frequented closer rivers and lakes (Non-Attenders 62.5 per cent vs. Attenders: 54.5 per cent chose rivers or lakes; Non-Attenders: 28.6 per cent vs. Attenders 33.3 per cent chose water pumps). From these numbers it can be assumed that Attenders possibly tend to walk longer distances to get uncontaminated water. Another explanation was that Non-Attenders live more remotely where there are no water pumps available.

The national census in 2003/2004 reported as mean number of cattle in rural areas: 13.6 cows. (National Bureau of Statistics - Tanzania, 2009). Non-Attenders as well as Attenders owned less cattle than that. Non-Attenders had in average 7.4 cows and thus more than Attenders who owned 6.5 cows in average.

While owning slightly more cattle, Non-Attenders on the other hand were worse equipped with any form of mechanised transportation. More than twice as many Attenders, compared to Non-Attenders, had even more than one bicycle available within the family. That fact shows, that Non-Attenders had to reach the clinic on foot (or mount) or had to borrow some other form of transportation more often.

In general, there are factors that lead to the assumption that Non-Attenders are poorer and/or live more traditional.

A minor difference was found concerning working hours per day. Non-Attenders worked less as well on days with seizures (0.3 h less) as on days without seizures (0.5 h less).

Altogether, the socioeconomic status represents an important indicator for adherence behaviour as described amongst others by Modi and colleagues (2011). With their study, conducted in Ohio with 214 CWE, they even showed that the socioeconomic status was the only significant indicator of non-adherence and they recommended to identify patients with the highest risk (Modi et al., 2011).

Without any doubt, poverty, epilepsy and non-adherence are part of a vicious circle. Epilepsy can bring poverty, for example by stigma, due to non-productive periods because of seizures, by side-effects or injury where an altered cognitive function is only one of them. Poverty again may hinder the patient accessing health facilities.

A poorly established national health system is an additional burden to participate regularly in follow-ups, especially for indigent parts of the population.

The Tanzanian Government recognized this challenge and stated in 2011: “The health sector in Tanzania is facing a serious human resource crisis which negatively affects the ability of the sector to deliver quality health services. There is a severe shortage of human resource at all levels. The shortage is more severe in rural districts […]. According to proposed staffing level in 2005, the existing health facilities required 125,924 health workers while the actual professional staffs available were 35,202 (24 per cent) indicating a deficit of 90,722 (76 per cent) for both public and private health and social welfare services.“ (National Bureau of Statistics - Tanzania, 2011). The mentioned discrepancies in numbers are tremendous and are suggestive of the problems the national health system is facing.

In their review of literature concerning worldwide adherence-behaviour, Jin and colleagues also identified the availability and accessibility of healthcare systems as a key-factor for a fortunate adherence (Jin et al., 2008).

At the time the study was conducted, Haydom Lutheran Epilepsy Clinic could give medication to PWE for free. Donators had borne the expenses, because just as in other regions of Tanzania, also in the Manyara region it seems impossible to encumber PWE or their family with the costs. This is, for example, also described by Jilek-Aall and colleagues in a study conducted in the Mahenge area (Jilek-Aall et al., 1997). Frequently PWE are in some way disabled and therefore unable to earn money. Their relatives are overburdened. If PWE were now or in foreseeable future obliged to pay their AED, another adherence-fall-out certainly would take place. As described in literature, especially poorer people avert from treatment as other things of daily life are more vital to them.

As the distance to the HLH was a major hindrance for a lot of patients, another option for PWE was visiting the next dispensary. In Tanzania, dispensaries serve up to 10,000 people. There are 4,940 dispensaries in the country, of which the Manyara region has 129 (National

Bureau of Statistics - Tanzania, 2011). The importance of these facilities is displayed by 14.6 per cent of Non-Attenders who regularly received drugs from a dispensary.

In Germany, for example, in economic terms PWE are as far as possible on the same level as people without epilepsy by getting compensation payments, handicapped ID pensions, etc. In Tanzania as in most developing countries there is no adequate national provision for handicapped people.

Thus, it becomes clear that economically weaker members of society and those who live more traditional and remote from bigger cities are underprivileged.

It would be an important point to make PWE understand, that some of the described hardships could be rectified by a good control of seizures and thus, that adherence and drug compliance was profitable in several aspects.

7 EDUCATIONAL ASPECTS

During our stay in the Manyara region we saw primary schools in many of the towns and villages. Children wearing school uniforms were often omnipresent.

As it was likely to find a young patient in a school, we frequently entered school facilities. From a middle European perspective, the immense amount of discipline demanded from the pupils was astonishing. Some teaching methods, however, appeared antiquated including the use of physical violence. In any case, thanks to Nyerere´s efforts from the 1960's to the 1980´s, Tanzania shows a remarkably high rate of primary school attendance, as being at 98 per cent of the relevant population stated by official authorities between the years 2008-2012. No less than 92 per cent of the population completes primary school. The literacy rate since 1988 is at a stable level of 76 per cent (UNICEF, 2014).

Of all PWE considered in this study, about 70 per cent were visiting or had completed primary school, while 30 per cent have failed to complete it. These numbers showed no significant difference between Attenders and Non-Attenders. Overall, the mean school-entry age was 10.8 years without any difference between Attenders and Non-Attenders.

The issue of a comparatively lower educational level of PWE was investigated several times and not only in developing countries. PWE are not only deprived of education by occasional absence from school after having experienced a seizure, but also by neurodevelopmental disorders or learning- and behaviour disorders, that many patients have (Msall et al., 2003). Anticonvulsive medical treatment and frequent clinical or subclinical seizures associated with impaired vigilance can have an additional influence on educational achievement (Aldenkamp et al., 2005).

Facing stigmatization, shame or fear of suffering a seizure in the presence of others, also may keep children from attending school. This effect is documented in developed countries and it is even more comprehensible for a less developed country like Tanzania. In suchlike countries, access to education is fraught with obstacles. A child weakened by a previous seizure having to manage the long walk to school may be just one of them. Furthermore, there is the almost omnipresent belief in epilepsy as an infectious disease or a demonic possession (Jilek-Aall et al., 1997) making stigmatization and uncomfortable feelings among fellow pupils, teachers and the patient themselves even more probable.

It is supposed that teachers are overstrained and therefore no real motivation for regular school attendance. It may be reasonably assumed that, similar to European educators, Tanzanian teachers have significant deficits in knowledge about epilepsy. Half of the

teachers in a study conducted by Prpic believed that CWE differed from healthy children in their behaviour

Providing teachers with reliable information about epilepsy is a simple intervention that could bring about positive effects. (Aguiar et al., 2007; Prpic et al., 2003).

In developed countries parents as well as teachers tend to be overprotective when dealing with seizures that were experienced at school or with overexertion and adverse effects of antiepileptic drug (Aguiar et al., 2007). There are multiple determinants of poor school performance of PWE in Nigeria, but psychosocial factors are considered as most important in a study of Adewuya and colleagues. The main reasons named were: poor family functioning, adolescents' felt stigma, adolescents' externalizing symptoms, and duration of illness (Adewuya et al., 2006).

Results of our study aim in a similar direction. Attenders generally tended to go to school more regularly than Non-Attenders (45.4 per cent vs. 35.5 per cent). Non-Attenders mostly gave socio-economic reasons for their lack of attendance.

Among the cohort, the following reasons to not attend school were given: About one quarter of the participants stayed at home longer out of concern for physical health. This was especially the case when the journey to school was long or the child was less resilient than others. When patients missed too much school and couldn't follow the lessons any more, they stopped attending school. Another reason was the need to relax and recover after a seizure. Stigmatization also played a role: Patients felt ashamed and thought being treated as inferior. Socio-economic reasons were brought forward nearly three times more by Non-Attenders than by Attenders. In practical terms this meant that the children were needed at home to care for siblings, to help in the fields or watch the cattle. So, the family couldn't afford to send them to school, also because there was no money for uniform, books, etc.

Some degree of mental impairment had kept 10 per cent of Attenders from going to school. They had not reached the necessary intellectual level and a specialised school was not available.

In current scientific literature, there was no data found to indicate whether PWE, who are not attending follow-ups regularly, also attended school less frequently. After all it has to be considered that in spite of a high share of people having attended school still 30 per cent of the Tanzanians are illiterates, this suggests that that level of knowledge cannot be directly related to school attendance. It might be interesting to compare pupil´s progress of Attenders versus Non-Attenders. Regrettably, this item was neither questioned nor tested (e.g. by a writing test or solving mathematical problems).

8 LIVING IN COMMUNITY AS A PATIENT WITH EPILEPSY: PERCEPTION OF EPILEPSY AND STIGMA

8.1 Stigma by epilepsy in Africa and worldwide

Worldwide there is stigmatization by epilepsy. Manifold studies and reports can be found on the existence of stigmatized PWE in high income countries (Baker et al., 2000; MacLeod et Austin, 2003; Tröster, 1997). Low income countries are not excluded from this phenomenon (Baskind et Birbeck, 2005; Carod et Vazquez-Cabrera, 1998; Jacoby et Austin, 2007; Jilek-Aall, 1999; Jallon, 1997). In high income countries children and adolescents with epilepsy have to struggle with teasing by others and feeling excluded from peer groups. As adults they suffer from psychosocial problems and prejudices in daily life (Chin, 2012). More importantly, in most parts of Africa stigmatization can often become life threatening or can at least lower the quality of life of PWE.

An existing belief in supernatural powers contributes to the stigmatization of sufferers from epilepsy (Jilek-Aall, 1999). This kind of belief is also part of Europe's recent past. Only a few decades ago, epilepsy was thought to come from demonic possession and was to be cured by exorcism (Jilek-Aall, 1999). As an anecdote, Jilek-Aall reports from some modern theological proponents (Catholics as well as Protestants) who formed the idea, that the demon might also affect the EEG curves (Jilek-Aall, 1999). So, it seems even more understandable that in African countries, where still many natural phenomena are seen and explained as supernatural, a PWE shaking and screaming, foaming from the mouth and with white eyes is seen as a demoniac or thought to be jinxed. These kinds of traditional beliefs throw the gates wide open for explanations of epilepsy being caused by divine punishment, ancestral spirits' wrath, demoniac possession, witchcraft, or poisoning (Jilek-Aall, 1999). As a consequence, preventive measures were thought to be identified in some regions of Africa and various personal behaviours were thought to increase a person's inclination to epilepsy. For example, bathing at night or collecting water after dark by pregnant women were seen as a kind of trigger and needed to be avoided (Coleman et al., 2002).

Also within the region, the study was conducted, supernatural ideas and scientific background concerning the perception of epilepsy seemed to coexist nearly as half and half (Winkler et al., 2010).

8.2 About stigma

Stigma research has generally characterized it as “felt” versus “enacted”. Enacted stigma manifests itself as discrimination against a person. The stigmatized person, therefore, experiences prejudice, discrimination and disadvantage as a consequence of their particular condition. Any kind of violence against the affected person belongs to enacted stigma. On the other hand, felt-stigma is defined as the decrease of a person’s self-esteem or sense of self-respect due to the individual’s perception that they are socially unacceptable. Individuals internalize stereotypes, apply negative public attitudes to themselves, and suffer diminished self-esteem and self-efficacy. (Vogel et al., 2013). Felt stigma also includes the individual’s fear of an enacted stigma. At least in high income countries, research shows, that with epilepsy enacted stigma and labelling is relatively rare (Kelly, 2009), but felt stigma is experienced more often (Kelly, 2009).

8.3 Stigma from perception

In our cohort, PWE and their relatives were facing 40 years of work of a western-oriented hospital nearby, but were still lacking modern explanations for epilepsy, i.e. at least a more scientific view of the neurological disease.

Even though it was explained to all PWE and their accompanying relatives when diagnosis was made, only 10.6 per cent of Attenders and even only 3.6 per cent of Non-Attenders had a profound knowledge about the medical causes for epilepsy. The percentages of Non-Attenders vs. Attenders differed only marginally when it came to supernatural explanations (witchcraft, „human hand“, spirit, curse). All in all, 36.9 per cent indicated these explanations as reasons for epilepsy. As quite often descendants also suffered from the disease, 1.6 per cent believed, the disease can be inherited. One quarter of the participants didn’t give any idea or viable explanation.

Asked about the medium influencing their perception, again by trend more Attenders indicated having been instructed by medical staff (9.1 per cent Attenders vs. 3.6 per cent Non-Attenders). Apart from that, “common belief“ was the answer given most often by both parties.

The widespread beliefs in supernatural reasons for epilepsy in SSA is specified in literature. By intensive field work, Jilek-Aall and colleagues contributed particularly to a detailed picture of the problematic explanatory models (Jilek-Aall et al., 1997).

In a study conducted in Tanzania, Dilip and colleagues reported that people’s explanations for epilepsy were the following: 40 per cent believed in a bird called Degedege, 30 per cent in an evil spirit and 20 per cent in a spirit in general. He suggests simplifying the access to

health care especially for illnesses, that are perceived as not belonging to the biomedical field. ”Communication campaigns“ could gradually loosen established traditional beliefs. The notion of a meliorated health and seizure situation could convince the people in the long-term (Dillip et al., 2012). A similar idea was developed by Louise Jilek-Aall and colleagues within the Abstract “Morbus Sacer”, describing a community where an epilepsy clinic was well integrated. After some time, the people could easily accept and internalize a biomedical explanatory model (Jilek-Aall et al., 1997).

Similarly, to a study conducted in Gambia (Coleman et al., 2002) and even though the reasons for suffering from epilepsy were mostly seen as supernatural, a high level of acceptance and integration was shown to people with the disorder.
Most of the people with epilepsy within our rural study area were living in a family setting. Mostly, their relatives carried the heavy burden of caring for them. With very few exceptions, PWE were generally not neglected or starving, as also illustrated for example by Mrs. Jilek-Aall (Jilek-Aall, 1999). A discriminatory atmosphere within the family was rarely obvious, with some exceptions.

Even though Non-Attenders tended to estimate themselves on the whole as being more effective than Attenders concerning their contribution to the work force, a sizeable group, i.e. 26.8 per cent of Non-Attenders compared to 21.2 per cent of the Attenders, felt as if they were less valuable for their community.

V. CONCLUSION

We found diverse reasons which presumably contributed to patients' non-adherence to medical treatment concerning epilepsy.
Most important seemed to be the distance to the hospital, which was longer for Non-Attenders.
Adolescent and pubescent patients also were more likely to show poor adherence.
Being economically weak and/or living a more traditional lifestyle seemed to have a negative impact on adherence.
Those patients who were on AED before first registration at the Haydom Lutheran Epilepsy Clinic significantly more often stayed adherent.
Previous data also revealed that patients who early dropped out of follow-ups in all probability would not become adherent later on.

POSSIBILITIES TO SUPPORT PATIENTS' ADHERENCE BEHAVIOUR

Based on the differences between the group of Attenders and Non-Attenders and influenced by the suggestions of relevant literature on adherence-research (see chapter Introduction I.2.4; page 13), we propose the following support measures for patients in this region.

1. Decentralisation

The distance to HLH as a barrier to biomedical health services was a recurrent theme and a common reason for non-attendance was the distance to HLH. We therefore recommend further decentralisation of care, if possible down to community level. At the same time there should be well trained staff on-site.
Epilepsy services should be improved in the community. A possibility would be extension services (a satellite clinic model) and collaboration with neighbouring hospitals. Thus, the provision of services to the neglected population in rural areas would be secured by reducing the distance the patient would have to cover otherwise.
Tackling the problem of the distance could also mean handing over the responsibility for patients' medical care to dispensaries. This would include securing their drug supply, but also their being appropriately educated about the illness. Additionally, an efficient and reliable connection to HLH should be given.
The initial assessment, diagnosis and prescription could take place during focused visits by trained staff of HLH, including community nurses. For prescriptions it is required not only to

prescribe the kind of drug, but also a certain amount of it, which again must be made reliably available at dispensaries.

2. Integration of epilepsy in Primary Health Care and a systematic development of specialised management programmes

Though epilepsy is one of the most frequent diseases in Sub-Saharan Africa (SSA), it is still neglected in primary health care. Epilepsy numbers among the non-communicable diseases in SSA. It would be a cost-effective way to deliver epilepsy services through primary health care. Guidelines for treatment should be developed and evaluated.

Similar issues exist for other chronic diseases. Tackling them all in an integrated primary care programme would form a systematic approach with an increased chance of sustainability. This would involve strengthening and mobilizing all primary care workers.

Primary-level management of epilepsy could be integrated into a chronic disease programme covering hypertension, diabetes, asthma and mental health. Initial diagnosis and prescribing could take place away from the periphery.

Target-oriented epilepsy management programmes and communication strategies are necessary to improve adherence and to avoid clinical consequences of poor adherence.

People with epilepsy are usually not in a position to organize themselves to exert pressure on health services to provide appropriate treatment or improve primary prevention.

The same is true for people with other chronic conditions. It is necessary for health care planners to be proactive in discussing the development of such programmes.

(Coleman, Loppy et Walraven, 2002)

3. Education on another level

In many parts of SSA, notions about epilepsy are rooted not in a medical model but in a spiritual model. This model derives epilepsy from an external/spiritual cause. Therefore, the affected person is seeking a contextually relevant cure that removes the alien factor from the body. Consequently, they are not and cannot be aware of a preventive or biomedical treatment.

Although all patients of our cohort got information about epilepsy when it was diagnosed, they seemed to fall back into their common traditional beliefs. Their image of epilepsy was still shaped by beliefs in an external spiritual cause which was commonly expected to be cured but not to be prevented.

Our findings indicate that it is necessary to take more than medical aspects of health education into consideration. Approaching and educating local people is the key factor for

this new way of comprehensive health education. To do so, the most receptive community members should be identified, local skills have to be bolstered and constraints have to be recognized. Ideally education was provided in varied approaches.

4. Security in regular supply of affordable medication

AED must be free or at least very reasonably priced. Moreover, it must be available at all times. If AED is to be paid it should be paid per year, as it might be squandered otherwise. Furthermore, having to handle with money every day is an extra burden to health workers, but also poses a risk to their personal safety due to possible robberies.

5. Cooperation with traditional healers and acceptance of traditional structures

Collaborating with local Mgangas (traditional healers) could create a fortunate situation for all parties involved. Mgangas might also be mediators. So, an understanding of community-based traditional medicine would not only offer access to those who abandoned western medicine but it would also help to recognize the patients' and relatives' true needs in this kind of cultural context.

We support Diop's idea of accepting and respecting, that people living in rural areas have special perceptions and attitudes, which, even if not understandable for us, might strengthen the cohesion in families, for example a peculiar handling of the ill persons (Diop, 2001).

This way, non-adherent behaviour can be tolerated (as far as it is not determined by external factors) as a form of self-determination, while at the same time still keeping up a low threshold service in case the Patient decides for biomedical treatment one day.

Summing up, traditional health and belief systems should be recognized and interventions must be built upon an already existing local practice.

Biomedical services do not seem to answer all the needs of people with epilepsy; psychosocial support takes time und and is not easy to give within anonymous and sterile examination rooms. It is often better given by traditional healers.

6. Focussing on felt Stigma and psychosocial support

Our results show that also in our sample stigma is a major burden. Even if it is 'felt stigma' that plays a bigger role than 'enacted stigma'. Other studies done in SSA come to this conclusion, too. Felt stigma may motivate PWE or relatives to delay help seeking and so contributes to non-adherence. Helping the people to less feeling stigmatized could be a

starting point for help. Possible measures could be twofold: On one hand there should be extensive and detailed conversations with patients and their relatives. On the other hand, by involving PWE whose treatment shows good results and who are willing to talk about it, the public as well as town communities can be informed and educated. These measures would contribute to a better personal and public understanding of epilepsy and thereby reduce the risk of stigmatisation – felt and enacted.

Many participants described the challenges in the lives of PWE and their families, stressing the fact that epilepsy brings about a range of other problems: physical, financial, social and cultural. Several families described how epilepsy had affected their children's development.

These findings emphasize the need for a substantial support especially for PWE and their families, because they have an additional challenge to overcome before having the same living conditions as healthy people in their surroundings. Medication should stay free or at least be really cheap. If possible, a fund should be set up to compensate for costs PWE and their families are going to have. This fund could be made up by donations or even taxes.

Best practice would be stately measures similarly to the German “Handicapped Status” to which several supporting measures are assigned. This could be done not only for epilepsy, but also for other chronical diseases.

7. Awareness of relevant predictors of non-adherence

Revising the data of the source population we found out that by means of certain characteristics, Non-Attenders could have been identified at an earlier point in time.

Particularly it became apparent, that

- patients, who were already on medical treatment when being registered, later on tended to adherence.
- patients, who occasionally missed follow-ups within the first months after registration, turned to become Non-Attenders eventually.
- patients, with a positive family history concerning epilepsy showed non-adherent behavior more frequently.
- patients, who achieved a striking reduction of seizures by treatment (namely coming from averaged 10 seizures/month, reporting after treatment averaged one seizure/month), were more inclined to be non-adherent.
- Non-Attenders were more often pubescent at the time of registration than Attenders

Considering those five aspects, a large part of the Non-Attenders could be identified at an earlier stage and possibly be informed more purposefully and thus managed more effectively.

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VII. LIST OF TABLES

VIII. LIST OF FIGURES

IX. APPENDIX

Questionnaire

1. Demographics:

Date: _____ **Name:** _____

Patient number: _____ Age: _____ Gender: _____

Tribe: _____ Religion: _____ Occupation_____

Marital status: _____ Age when married _____ N° of children: _____

Head of househ.: _____ TCL: _____ Witness: _____

Address: _____

Distance to Hospital: _____ means of transport:_____ time:_____

2.1 Description of seizure(s):

Description by patient and/or witness (use opposite side):

Loss of consciousness: from the beginning after motor signs start no loss

Motor activity: tonic clonic both no movements at all

Side of limb movements: only left side only right side both sides

Fitting for how long? _____ ever fitted >than 30 min, if yes give time? _____

Supportive signs: froth from mouth tongue/lip bite urine/faecal incontinence

Reorientation phase? no yes How long?_____

Description of Reorientation phase: _____

Are seizures always the same? If different, describe and make clear to which type of seizure(s) the information in the questionnaire refers to? _____

2.2 Frequency:

When did fits start? Year: _____ Age: _____ Last fit: _____

Avg. frequency before Tx: _____ Avg. frequency under Tx: _____

Current frequency: _____

2.3 Prodromi/Aura:

Seizures start suddenly Pt. knows when they are coming

Description of sensation: _____How long before:_____

2.4 Precipitants: yes no

Any precipitants that bring seizures on? Fever alcohol menstruation sleep

emotional stimuli other:_____

2.5 Past Medical History

Description of severe/chronic illnesses in the past (type, date, action taken, permanent condition):_____

_____

Febrile fits in the past? Describe_____

_____

_____Accidents,

injuries or traumata (type, date, action taken, permanent condition):_____

_____Hospital admissions (what hospital, reason, date, time of stay):_____

_____

_____

When and where was diagnosis of epilepsy made for the first time?_____

Time from first seizure to first presentation (month or years) _____

2.6 Past Psychiatric History

yes no

Description of psychiatric problems in the past and at present: depression mental retardation behavioural problems dementia psychotic episodes other:_____

Severity: mild moderate severe since when: _____

action taken:_____

Is the start of psychiatric problems connected with epilepsy? Yes No

2.7 Drug History

Are you currently on Tx besides AED? no yes, details_____

Are you currently on AED? no yes:

Phenobarbitone Dose:_____ started when:_____ where:_____

Carbamazepine Dose:_____ started when:_____ where:_____

Valproate Dose:_____ started when:_____ where:_____

Other Dose:_____ started when:_____ where:_____

Frequency of fits on current drug:_____

Side effects: no yes: Dizziness tiredness headache nausea skin rash other:_____

slight medium severe

Tried other AED? no yes:

Phenobarbitone Dose:_____ started when:_____ where:_____

Carbamazepine Dose:_____ started when:_____.where:_____

Valproate Dose:_____ started when:_____ where:_____

Other Dose:_____ started when:_____ where:_____

When stopped:_____

Frequency of fits on other drug:_____

Reason for changing: side effects no response other:_____

Do/Did you feel relief from epilepsy while taking AED? Yes No

2.8 Attendance of HLH and Compliance

Last appointed Follow-up:_____ Attended: yes no

Last time at HLH or other Hospital: _____

Why: Appointment Fit Other disease Other reason: _____

How often visiting Follow-ups per year: _____

Reasons for not coming: Lack of money No time No fits anymore Rough journey Treatment somewhere else Not satisfied with results of treatment Problems at home (which?) Alternative/herbal treatment (specify) Was told by somebody else not to attend the hospital (specify)

Other reason(s):_____

Specifications:_____

_____

_

How could regular attendance be made easier for outpatients?_____

_____

_____

What would be/is a reason for coming to the Hospital?_____

_____

How far is the next dispensary away? _____ Do they distribute AED? Yes No

Would you prefer to get AEDs from there? Yes No

3.1 Social life

Married Previously married Remarried Polygamous Monogamous

How old is the partner? _____ If polygamous, what position is the patient? _____

If not married, reasons? Social Financial Epilepsy Age

. other reasons: _____

How many children do you have?_____

If no Children, reasons? No Wish Epilepsy Health Problems (Husband/Wife)

. other reasons: _____

. Children who died? _____

Ever been abused/mistreated? Yes No Sexually abused Raped Physically abused Insulted because of epilepsy? Yes No

. Details: _____

Situation in Community, as you perceive it, compared with other women/men:

Similar/the same better worse

If better or worse, explain: _____

_____

_____

Do people in your community know about your disease? Yes, I told them Yes they know it from somewhere/they saw me having a fit No, they don't know

Do you feel people - are uncomfortable with you? Yes No

. - treat you like an inferior person? Yes No

. - would prefer to avoid you? Yes No

Why do you think that might be? _____

_____

_____

Description by patient and/or relatives

Who cares for the patient at home?_____

Can he/she help at home with daily work?

What is his her role in domestic life? No help at all little help equal member of social group

Comments:_____

3.2 Social / Economic Status

Do you have a home or are you roaming the streets? Home Streets

What is your profession?_____

What is your spouse's profession?_____

How many people live in your household?_____

Do you have electricity at home? Yes No

Where do you get water from? Tap Waterpump River

How far to have to go to get water (min)?_____

Do have bicycles, cars, if yes, how many? No Yes: _____

Do have cows or goats? If yes, how many? No Yes: _____

Waste management: Toilet in dwelling Toilet nearby Pit latrine Bush

Food security:

two or more meals per day

skipped meals in past week

≥1 day without food in past week

Number of meat, poultry, or fish meals per month

Fewer meals in hunger season

Healthcare use:

When being pregnant/giving birth, do you come to the hospital? Yes No (specify)

_____

When you are seriously ill, would you go to the hospital, if no, give reasons. Yes No (specify)

3.3 School

Did/do you go to school? yes no, reason:_____

Age started?_____ Level achieved?_____

Regular attendance? yes no, reason: epilepsy financial social

other: _____

Drop out? yes no, reason: epilepsy financial social

other: _____

3.4 Work

Before first fit: Type of work?_____ Hours of work?_____

Since fits started: Type of work?_____ Hours of work?_____

Since Tx started: Type of work?_____ Hours of work?_____

If there is a difference, give reason:_____

_____

After fit: Days lost due to fits: _____Days with impaired work:_____

On days with impaired work pat works: <50% > 50%

4. 1 Traditional Treatment

Herbal Tx tried? yes no, description (what ingredient, when started, for how long taken, any help, side effects):_____

_____

Scarifications performed? yes no, description (when, where, manipulation of wound, any help, side effects)_____

4.2 Perceptions of epilepsy

What do you know about causes of epilepsy?

Scientific background Witchcraft/Curse Infectious Punishment Inherited

Other ideas: _____

From whom do you know? Medical staff Family/People of community School Active search for information Common belief

How can you cope with the disease? Very good good fair bad very bad

Future visions, plans?_____

5. Alcohol Consumption

Do/did you drink alcohol? Yes No

Age when started:_____ Age when stopped: _____

How many times per week? _____ What kind of drink? Piwa Beer Konyagi

Other (specify) _____

How much of it?_____

How often drunk? ___ per week/month/year

Ever been sick or admitted to hospital because of alcohol? specify

How much money is spent per month on average? _____

Have you recognized a connection between alcohol and seizures? Yes No

Not working because of alcohol?

Details:_____

_____

_____

6.1 Development

Milestones:

(All compared to same aged children)

Delayed ? normal?

Head control	turning	sitting	crawling	standing	walking	talking

Delayed since when: since birth special event:_____

Neonatal seizures (age, frequency, any associated symptoms/signs)_____

6.2 Neurological signs

Cranial nerves: _____

_____

Power: Upper Extremity

Lower Extremity

Reflexes: TSR BSR RPR PSR ASR

Babinski-Reflex

Comments:_____

Coordination:

Sensation : Upper Extremity

Lower Extremity:

Comments: _____

6.3 Mental State

Appearance normal abnormal:_____

Behaviour normal abnormal:_____

Cooperation normal abnormal:_____

Affect normal abnormal:_____

Speech normal abnormal:_____

Mood normal abnormal:_____

Thought normal abnormal:_____

Cognition normal abnormal:_____

Ethical Clearance

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NIMR/HQ/R.8c/Vol. I /33

21 August 2007

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APPROVAL FOR PROTOCOL AMENDMENT

This letter is to confirm that your application for an amendment on of the already approved protocol on: Neurological disorders with emphasis on Epilepsy in the catchment area of Haydom Lutheran Hospital, Arusha region, northern Tanzania. (Winkler A *et al*) NIMR/HQ.R.8a/Vol.IX/137 dated 13th June 2003, has been granted.

The amendment approval is for the following sub studies for the two students:

1. Causes of decreasing numbers of outpatients at the Haydom Lutheran Epilepsy clinic. The course of epilepsy in defaulters compared to patients under regularly controlled treatment (Barthelmes S).
2. Electrophysiological confirmation of clinically based diagnoses of epilepsy at the Haydom Lutheran Hospital (Kampmann A)

Name: Dr Andrew Y Kitua

Signature

CHAIRMAN
MEDICAL RESEARCH
COORDNATING COMMITTEE

Name: Dr Deo Mtasiwa

Signature

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RESEARCH PERMIT

No. 2007 –324 – NA – 2002- 98 Date **17th September 2007**

1. Name : **Sylvia C. Barthelmes**
2. Nationality : **German**
3. Title : **Electrophysiological Confirmation of Clinically based Diagnoses of Epilepsy at the Haydom Lutheran Epilepsy Clinic**
4. Research shall be confined to the following region(s): **Manyara and Arusha**
5. Permit validity: **17th September 2007 to 16th September 2008**
6. Local Advisor/collaborator: **Dr. Mwele Malecela, NIMR, P.O. Box 9653, Dar es Salaam**
7. Researcher is required to submit progress report on quarterly basis and submit all Publications made after research.

M. Mushi
for: DIRECTOR GENERAL

Eidesstattliche Versicherung

Barthelmes, Sylvia

Ich erkläre hiermit an Eides statt, dass ich die vorliegende Dissertation mit dem Thema selbständig verfasst, mich außer der angegebenen keiner weiteren Hilfsmittel bedient und alle Erkenntnisse, die aus dem Schrifttum ganz oder annähernd übernommen sind, als solche kenntlich gemacht und nach ihrer Herkunft unter Bezeichnung der Fundstelle einzeln nachgewiesen habe.
Ich erkläre des Weiteren, dass die hier vorgelegte Dissertation nicht in gleicher oder in ähnlicher Form bei einer anderen Stelle zur Erlangung eines akademischen Grades eingereicht wurde.

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